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ABSTRACT

Ten papers are presented from a 1984 conference on research priorities in deaf-blindness. Each of five areas is examined first with a review of the literature and second with priorities for future research, summarizing the recommendations of the 10-member group. Responses to questionnaires sent to rehabilitation counselors, university affiliated service centers, programs, and state rehabilitation directors were also incorporated. The following five broad areas were examined: (1) demographics and population characteristics research; (2) psychological, developmental, and clinical research; (3) educational and school-based research; (4) rehabilitation and job-skills development research; and (5) technological (aids and device development) research. Authors of the papers are as follows: Raymond J. Trybus, Douglas Watson, Myra Taff-Watson, STephen Barrett, Wanda Hicks, Asa De Matteo, James E. Stahlecker, Roger Freeman, John Reinman, Theresa Smith, Jan Writer, Steven Machalow, Paul Cotten, Steve Bolgrin, William H. Graves, Rod Ferrell, Lawrence A. Scadden, and Deborah Gilden. (CL)

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STATE-OF-THE-ART:
RESEARCH PRIORITIES
IN
DEAF-BLINDNESS

Proceedings of a Conference

Sponsored by:

THE NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

AND

THE UNIVERSITY OF CALIFORNIA RESEARCH AND TRAINING CENTER ON MENTAL HEALTH AND DEAFNESS

in collaboration with:

RESEARCH AND TRAINING CENTER ON BLINDNESS AND LOW VISION AT MISSISSIPPI STATE UNIVERSITY

REHABILITATION ENGINEERING CENTER AT THE SMITH-KETTLEWELL INSTITUTE OF VISUAL SCIENCES

RESEARCH AND TRAINING CENTER ON DEAFNESS AND HEARING IMPAIRMENT AT THE UNIVERSITY OF ARKANSAS/LITTLE ROCK

2-5 November 1984

Washington, D.C.

Edited by:

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STATE OF THE ART: A CONFERENCE ON RESEARCH IN DEAF-BLINDNESS

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STATE OF THE ART: A CONFERENCE ON RESEARCH IN DEAF-BLINDNESS NOVEMBER 2-5, 1984

CONFERENCE OUTLINE

This four day conference, held at the Capitol Holiday Inn in Washington D.C., brought together a select group of professionals from around the nation to establish priority concerns for future research in the field of deaf-blindness. Fifty invited participants, including university teachers and researchers, rehabilitation administrators and service providers, government agency workers, and deaf-blind consumers, met to: 1) discuss the current "state-of-the-art" in research pertaining to deaf-blindness; and 2) establish needed avenues of investigation for future research.

A planning session for the conference met in April, 1984. That group was comprised of representatives from the four RTC/REC Centers on Sensory Impairment (U. of California Center on Deafness, U. of Arkansas Center on Deafness, U. of Mississippi Center on Blindness, Smith-Kettlewell Institute of Visual Sciences), the National Council of State Administrators of Vocational Rehabilitation, the National Council of State Administrators of Services to the Blind, the Department of Education (NIHR and SEP), and the American Association of the Deaf-Blind. The planning conference participants selected a site for the conference, established broad issues for the conference to address, defined the scope of the conference, and identified participants to be invited. Five broad areas of investigation were delineated for specific focus during the conference. They were:

1) Demographics and Population Characteristics Research
2) Psychological, Developmental and Clinical Research
3) Educational and School-Based Research
4) Rehabilitation and Job-Skills Development Research
5) Technological (Aids and Device Development) Research

Participants were identified and assigned to a particular group according to their particular area of expertise and/or interest. A single group leader/facilitator for each "core area" group was identified from the RTC/REC network. Additionally, an invited speaker for each group was identified from the list of invited participants. That individual, selected because of his/her particular expertise, was asked to draft a

review of the research literature pertaining to the group's area of focus. The reviews of literature were sent to the various group members prior to the November conference, and the invited speaker summarized that review orally during the first day's presentations.

Because the number of participants invited to attend the conference was so limited, it was decided to solicit wider field comment through a questionnaire survey. The purpose of the survey (sent out during the summer months to rehabilitation counselors for the deaf and the blind, university affiliated services centers, programs receiving federal assistance serving the deaf-blind, and state rehabilitation agency directors) was to solicit specific research questions which, from the perspective of the service provider, needed to be addressed by academic researchers. Comments were solicited in each of the five broad areas. Questionnaires from the field were gathered throughout the summer months. Comments were organized and summarized by each of the core group leaders and were presented, along with the group speaker's review of research, during the first day of the conference.

The conference was organized in the following fashion:

Day one	(afternoon only): presentation of research reviews and field comment summaries to conference participants
Day one	(evening): presentation by Director of NIHR
Day two	(morning): homogeneous small group work session for identification of pressing research needs
Day two	(afternoon): heterogeneous small group work session for identification of common concerns among various disciplines and agencies
Day three	(all day): homogeneous small group work session for identification of priority concerns for future research and identification of specific research questions to be addressed
Day three	(noon): presentation by Chair of Canadian Task Force studying deaf-blind population
Day four	(morning only): presentation of research priorities of each core area group to conference participants

The following chapters represent the effort of this four day conference. Two chapters are devoted to each core area: 1) the review of literature solicited prior to the conference and written by the core area's speaker; and 2) the priorities for future research, summarizing the recommendations of the ten member group on the basis of the comments from the field solicited by questionnaire and of their own group discussion throughout the conference itself.

SPECIAL THANKS

This conference may not have occurred except for the deep concern of Mrs. Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, about the needs of severely handicapped children and adults. It would not have occurred except for the insight of Dr. Douglas Fenderson, then Director of the National Institute for Handicapped Research and of Dr. Richard Johnson, Project Officer, the National Institute for Handicapped Research. They recognized the urgent need for information about ways to provide more appropriate services to deaf-blind individuals.

Neither could the conference have occurred without the always-present assistance of Brenda Talley who recruited the many interpreters needed and coordinated their function throughout the meetings. The interpreters who provided much appreciated services for the deaf-blind and deaf participants are: Sharon Carter, Earl Elkins, Lori Fields, Denise Gagnon, Kathryn Hamilton, Linda Humphreys, Charlene Laba, Eleanor MacDonald, Sue Mermon, Harold O'Connell, Karen Petronio, Suzy Pryor, Thelma Schroeder, Kathleen Stock, Brenda Talley and Christy Willis.

Thanks also are expressed to the Callier Center for Communication Disorders, University of Texas at Dallas, for allowing Dr. James Stahlecker to continue as Conference Coordinator after he accepted appointment there.

This volume could not have been published so quickly except for the efficient, effective work of Elisa Rleigh, who performed miracles on the word processor and was wonderfully pleasant to work with through it all.

Thanks to each!

J.E.S.
L.G.
S.M.

STATE-OF-THE-ART:
A CONFERENCE ON RESEARCH IN DEAF-BLINDNESS

WASHINGTON, D.C.

NOVEMBER 2-5, 1984

EXECUTIVE SUMMARY

JAMES E. STAHLECKER, PH.D., CONFERENCE COORDINATOR
CALLIER CENTER FOR COMMUNICATION DISORDERS
UNIVERSITY OF TEXAS AT DALLAS

LAUREL GLASS, M.D., PH.D., DIRECTOR
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UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

This conference, which drew together researchers and service providers having interest in the field of deaf-blindness, was convened as a means of establishing "priority concerns" for research. Dialogue between service providers, researchers, academics, and deaf-blind consumers allowed for systematic planning of research ideas and of goals, and hopefully will lead to the implementation of new work, and ultimately new service programs for deaf-blind individuals.

The conference divided participants into five areas of "specialty" (demographic research, psychological research, educational research, rehabilitation research, and technological research), and thus focused on concerns for research in several disciplines. Time was also allocated for participants to interact with members of other speciality groups, and several broad-based concerns emerged from those discussions across disciplines which deserve special attention here.

Without exception, each group emphasized the fact that the field of deaf-blindness has received little, if any, attention from the academic research community. Over and over, it was underscored that we simply do not know enough about the deaf-blind population in the United States to make many educated statements about what needs exist in that population.

Nearly every group stressed the imperative for demographic and descriptive information about the population--in terms of numbers, degree of vision and hearing loss, age of onset of each sensory disability, primary means of communication (both expressive and receptive), residential and work (if applicable) setting, and personal situation.

Identified by each of the groups was the common need to develop a comprehensive data collection system on the deaf-blind population of the United States. While the National Information and Referral Center on Deaf-Blind Children and Youth (terminated in late 1984) was responsible for collecting information from each of the Regional Centers on school-aged children, and the Helen Keller National Center collects information on adult deaf-blind citizens identified by their Regional Representatives, these systems have not been integrated and most likely do not represent an exhaustive estimate of the population.

A single mechanism for gathering information on all individuals with both vision and hearing impairment, regardless of age, regional location, educational placement, or eligibility for rehabilitation services is central to understanding the scope and magnitude of problems facing vision-impaired and hearing-impaired individuals. Only as the population can be more fully described, will truly relevant research and program ideas become a reality.

Secondly, each group addressed the importance of recognizing that the term "deaf-blind" serves a purpose only as a shorthand way of describing individuals with both hearing and vision impairment. The population of individuals with both sensory disabilities, however, is incredibly diverse. As research and/or service needs are identified, we must be ever-conscious of the fact that any single question of research or approach to service can, at best address only a segment of the population having a particular type of hearing and vision impairment with a certain set of communicative, self-help and personal skills. No appropriate research question should attempt to address "the deaf-blind" as a single entity, and no service program should be conceptualized as being capable of meeting the needs of all individuals with both vision and hearing impairment.

Finally, all groups addressed the important need for service continuity--not only continuity of service between provider networks (medicine, education, rehabilitation, social service, mental health)--but the temporal continuity of service needs as well. The nature of the double disability of deaf-blindness often requires a more comprehensive approach to service, and is likely to require service providers' attention to needs of the individual "around-the-clock". Comprehensive planning must not only provide for the education, rehabilitation, and health needs of the deaf-blind individual, but must be attentive to the living, personal, and recreational needs of those individuals as well.

The outcomes of a conference such as this one must go beyond the publishing of research priorities like those included in this volume. Each individual who reads must take the responsibility of lobbying for such research actually to take place with the appropriate federal, state, local and private support it deserves. Only as individuals, groups, and programs begin to address the research and service needs in the field of deaf-blindness, and lobby for its political and financial support will deaf-blind individuals truly be helped to fulfill their potentials.

Dallas and
San Francisco
31 March 1985

REDEFINING THE UNACCEPTABLE

DOUGLAS FENDERSON, PH.D., DIRECTOR
NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

Rehabilitation is a continuing redefinition of the unacceptable. Early in this century the waste of human productivity caused by accidents in heavy industry: mining, railroad building, became unacceptable. The rehabilitation solution was vocational retraining. Later, during and after World War I, additional emphasis was placed on physical restoration and improved artificial limbs and other prosthetic devices. However, those with severe injuries, such as paraplegia or quadriplegia, died within a few weeks or a few months--a sharp contrast to the nearly normal life expectancy at the present time. Epidemics and high prevalence diseases such as polio and tuberculosis, likewise presented unacceptable outcomes for those with disabling effects. Such conditions were a major stimulus to the development of the medical field known as physical medicine.

In fact, two physicians who wrote for the first Board Examinations in that field, Dr. Frank Kruzen from the Mayo Clinic, and Dr. Milan Knapp, from the University of Minnesota, both had very personal disability-related reasons for being interested in the subject. Dr. Kruzen was recovered from a severe case of pulmonary tuberculosis. Milan Knapp was a former orthopedic surgeon who became concerned with the very poor outcome of patients who were prescribed splints and braces, whose joints and limbs were immobilized following paralytic polio or other conditions. Then came World War II. Conventional wisdom said that sick people should be in bed. Prolonged bedrest following surgery and obstetrical delivery were essential to recovery. A young medical officer, Howard Rusk, found that conventional wisdom was unacceptable. Within limits of tolerance, patients on his wards including and especially those with acute pneumonias, were kept physically active within limits of their tolerance. The body, he reasoned, is made for use. Forced inactivity, except when absolutely essential, is unhealthy. Rusk developed an approach that he called rehabilitation medicine. After World War II the two fields merged and became physical medicine and rehabilitation medicine.

About this time, the most important woman in government service appeared on the scene. Her name was Mary Elizabeth Switzer. She found

the partial and fragmented approaches to be unacceptable. She found the general low level professional training of rehabilitation professionals to be unacceptable. She found the tendency to stereotype disabled people as "the handicapped" to be unacceptable. Many of the rehabilitation programs in the United States and, indeed, throughout the world, are a tribute to her far-sighted leadership. Since 1968 more than ten federal acts or amendments have recognized the de facto limitations on the rights of disabled persons and have shown them again to be unacceptable. These included the Architectural Barriers Act of 1968; Acceptable Mass Transporation Act of 1970, Accessible Highway Facilities Act of 1975, Section 504 of the Rehabilitation Act - 1973; and the Protection and Advocacy for the Developmentally Disabled Act - 1975; perhaps the most important bill, The Education for All Handicapped Act of 1975, the Independent Living Priority in the Rehabilitation Amendments of 1978, and the Social Security Amendments of 1980. In 1978, Congress passed another far-reaching piece of legislation regarding the unacceptable state of knowledge in the field of rehabilitation. This was Title 2 of the Rehabilitation Act and through it was established the National Institute of Handicapped Research (NIHR).

I am going to make a few brief comments about the important authorities in this act, some of our current activities, pertinent to your meeting and to our long-range plan, and finally some comments on how the result of this meeting might be turned to useful purpose. NIHR was established to emphasize the application of the methods and material of science and technology to the challenges of disability and the loss of normal function. That act removed age barriers from the research authority. It includes all ages from birth to old age. It encompasses the full range of participants: disabled persons, parents, advocates, educators, physicians, therapists, behavioral scientists (if that is not a contradiction in terms), engineers, and technologists, amongst others.

We were instructed in that law to develop a 5-year plan every 3 years and that 5-year-plan was not only to guide the research developments within NIHR, but was to be so good that it would provide guidance to the rest of the world of disabled affairs as well. In addition, the Director of NIHR was made responsible for convening quarterly an inter-agency committee on disability research. It turns out that there are some 29 federal agencies that have identifiable programs of disability research at combined budgets of about $200 million, of which NIHR is the largest single category; since I've been here, in two years that committee has met every quarter. It is assisted by eight subcommittees on various aspects of disability to further improve the communications across the various agencies of the federal government. We were also given the responsibility of developing a research utilization program to exploit telecommunications technology in closing communication gaps, and we were instructed to stay informed about what was going on in communications research throughout the world. How is that for a piece of legislation? We have made interesting and significant achievements in each of these areas and I would be glad to discuss any of those with you personally or through correspondence; however, I want to go on very quickly to mention a number of activities that NIHR supports that are pertinent to what you are doing here.

Obviously, pertinence has to be stretched a bit here, because you are dealing with a very discreet problem in which a great deal of research is lacking, and that is why you are here. All I can do is to suggest the major categories that are related to your areas of interest with the hope that these may suggest some possibilities with regard to your recommendations. I am a little embarassed going through this list, however, because I would guess that half of the people or projects that I will mention are here in this audience this evening--so please indulge me for a moment. I am going to organize them under four categories:

1) independent living;
2) technology;
3) psycho-social/vocational;
4) informational resources.

INDEPENDENT LIVING

We support three major projects in independent living. A 5-year research and training grant at the University of Kansas, studying such topics as administration of independent living centers, finance, performance evaluation, selection and training and supervising of care attendants. We support a project at the Texas Institute for Rehabilitation Research which extends these concepts under Lex Frieden's direction now into rural independent living activities. Lex places particular emphasis on peer counseling and advocacy.

We support another project through Western Washington University which provides linking arrangements in rural communities in a number of parts of the U.S., using local interest groups, local resources as well as a computer bulletin board to link up communities around the United States. That project reminds me of an advertisement by AT & T some years ago in Newsweek. It had a picture of New York City and the by-line at the bottom said "The technology that makes the city possible, now makes it unnecessary." The presidentially appointed Council on the Handicapped held a one day symposium with the leaders of the Independent Living Movement. They were concerned about the extent to which the independent living concept could be expanded to include excluded groups: mentally ill, mentally retarded, severely sensory impaired individuals, and also to extend the concept of acceptable outcomes of independent living other than the narrow definition commonly accepted. In a recent editorial in the UCP Newsletter, D. Clark Ross added an important perspective. He said: "The 1978 Amendment to the Rehabilitation Act established centers for independent living as a priority. Today over 100 such centers are to be found included in every state. The independent living movement, directed by physically disabled adults, has rejected professional and agency control of services and has advocated adult consumer and self-help leadership. Independent living centers must have substantial consumer

membership on all of their governing boards. This is a very healthy development as some groups of disabled people who in the past have perhaps been treated as adolescents, are beginning to assume greater independence and leadership."

TECHNOLOGY

I can pass over these very quickly--you are familiar with the work of Smith-Kettlewell--the spin-off of Jim Bliss' tele-braille device. It is interesting for me to note, though, that less than 10% of deaf-blind individuals would be able to use that device, simply because they are not skilled in the use of Braille. Although a number of marketing attempts have been made, including giving the devices away through California Bell--I understand that has been mentioned today--still the potential of that device is likely to be very limited, particularly at the quoted price. One estimate indicates that perhaps, at best, 500 people in the country might benefit.

We have an engineering project at Tufts University emphasizing the use of computers for non-vocal communicators. The Trace Center at the University of Wisconsin in Madison studies problems of interface accessibility for severely disabled individuals. We support work at the Lexington Center in New York on a whole new generation of hearing aids, using computer-like micro circuits as well as supporting work at Gallaudet in Washington, looking at new technologies for deaf individuals.

PSYCHO-SOCIAL/VOCATIONAL

In the psycho-social area there are a number of studies that we support looking at the interaction between children and parents, with the idea of assisting parents to create the most supportive and developmentally enhancing environment possible, while at the same time recognizing the severe problems of parents, their stresses, their concerns and their needs for respite care as well. I could mention a number of specific locations; if you are interested we can provide that information. I don't need to describe the program at the University of California in San Francisco. Those people are your hosts for this meeting and I will skip over that.

We have several projects under the Psycho-Social/Vocational area that represent a major goal of the Assistant Secretary, Madeleine Will. These are in the area of transition from school to work. We are supporting a number of investigations of model programs defining curricula for training of job coaches and other kinds of workers. We are participating in the development of a plan to which orientation will take place in each of the ten regional offices or through the ten regional offices in orienting key leaders in special education, rehabilitation and community based services

in relation to the transition from school to work. I need to make a comment about that in relation to the range of problems you are considering. Madeleine Will would say that we don't expect enough from severly disabled children in school, and we probably get what we expect. We should have curricula, starting at the junior high age, that begin to anticipate adult roles and, particularly, adult work roles. We need to have greater emphasis on vocationally relevant curricula in the senior high school years, including work activity or work experience programs.

Mrs. Will is committed to the proposition that except where absolutely necessary, institutions--in any of their forms--are unacceptable. She believes that very few people should be working in sheltered workshops. If they are so severely disabled that they require a sheltered workshop, she believes there is an alternative model called "supported work", where a job coach helps to locate the job, trains the person in the job context, orients the workers within that work context and provides follow-on supervision in the job for as long as that is needed and for the rest of that person's work life, if that is necessary. Mrs. Will has made a deep commitment to that and each of the three components in the office of the assistant secretary--special education, rehabilitation services and NIHR--are participating in this. In fiscal year 1985, an amount of about $11 million will be spent in various aspects of start-up, demonstration, evaluation and research in the transition model with special emphasis on the concept of supported work.

INFORMATION SERVICES

Finally, with regard to information services, we support a small grant in California with an organization known as Sensory Aids. It produces a newsletter and a quarterly catalog and the first computer bulletin board devoted specifically to blindness and I understand there is a tie-in between that and Smith-Kettlewell, so that whatever new technologies come on the market, they can be communicated readily.

We support the National Rehabilitation Information Center (NARIC). It is the repository for all rehabilitation research that has been supported by NIHR and its predecessor agency. It also contains a computerized file of whatever rehabilitation technology, assistive devices of various sorts, that are available.

FUTURE FUNDING OPPORTUNTIES

Quickly, let me move on to future funding opportunities and I will mention four of them. We have just selected our second class of rehabilitation research fellows: 17 research fellows for a 1-year fellowship paying $25,000 for post-doc type fellowships, then $30,000 for

more experienced fellows. Competition is considerable--we had 60 applications for 17 grants last year. Field-initiated research will be announced again in December. Last year in the first year of that program we received 372 applications--104 only were found to be technically meritorious, and of that number we had sufficient resources to fund only 48. We will announce a new program this year, mandated by Congress, called Innovative Grants. These are small, one-year grants, limited to a maximum of $50,000. They are meant for small projects, start-up grants, or testing of technological concepts.

Another category of things that you should be aware of and give us suggestions, is a small amount of money -- $200,000 -- that we have set aside for collaborative studies with the National Aeronautics and Space Administration. Space age technology can be accessed by people in rehabilitation and through collaborative agreements with NASA we can, with small amounts of money, leverage enormous technical advantages, so you should keep that in mind.

WHY THIS CONFERENCE

Now, I am going to comment on the question that was originally raised of me: what good is this meeting anyway? In one of my earlier incarnations, I was the Director of Continuing Medical Education at the University of Minnesota, and I can tell you that I have participated in thousands of meetings. A meeting like this is an occasion for learning and an occasion for contributing ideas. Most of what you will get out of it will be based on the initiatives you take in communicating personally and directly with other people here. That has been my unvarying experience. Far more important than any program are the personal communications that you initiate, that you become involved in. They are invaluable. Make the most of those. Secondly, to the extent that you can come up with some clear recommendations for action, it is not enough for you to transmit a report, but follow through and follow up is essential.

Let me tell you a story. In downtown Washington is the headquarters of the American Association for the Advancement of Science. There are two people on that staff who devote their entire energies to science and the disabled: Martha Rebon and Virgina Stern. They have held a number of conferences on technology for the disabled. At the end of their conferences they characteristically ask each individual to write out a personal set of goals that they will commit themselves to, based on what went on in the meeting. Then they ask for a copy of that and put a schedule of phone calls into their tickler file. They have been known to butt people up to a year with regard to the follow through on what they said was a good idea at the time they participated in that meeting. So it is possible for you to commit yourself to a course of action and to follow through to see that things happen.

Let me give you a second example. We've supported a number of these so-called State-of-the-Art conferences. One of them was on the question of rehabilitation needs of disabled Hispanic individuals. As a result of that meeting we received a long list of research goals. Subsequent to that we began to receive phone calls from the Texas Rehabilitation Commission to set up a Research and Training Center at Pan American University. Then we started to get letters from Congressmen, Senators and Representatives--"You people sponsored a program. The program resulted in certain recommendations, therefore we need a Center". As a matter of fact, we have funded one major project with Pan Am University--it is a project, not a Center, because the results of the conference did not warrant a Center, but the conference stirred up a great deal of interest, and gathered a great deal of support for one of the most important areas developed within that conference.

At the community level, recommendations that you have are unlikely to take root unless there is a set of shared goals, unless the commitments at the local level are sufficient to bring about change. The federal government can do some things, but only some things. Many more things are to be done in the private sector, in your own organizations and in the communities. So it is not sufficient to give the federal government only a list of action items for it to take care of; we can at best be co-partners with you.

I am going to conclude my comments tonight on the same theme as when I started. Rehabilitation is a continuing redefinition of the unacceptable. Progress in the past 84 years has been substantial and holds promise for what we can do together. I hope that in the next two days you will find some more things that are no longer acceptable.

CHAPTER 1

DEMOGRAPHICS AND POPULATION CHARACTER RESEARCH IN DEAF-BLINDNESS

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> "Planning for services to deaf-blind persons is severely hampered by a lack of relevant information and a lack of coordination and control of the service system due to its fragmented nature. Information on the prevalence and needs of deaf-blind persons over the age of 21 years is pratically nonexistent; nationally available data on younger deaf-blind persons is much better but still deficient. For example, data on the nature of the 'deaf-blind' person's degree of hearing and vision impairment, degree of functional sensory ability, degrees of other types of functional ability, and presence and degree of additional handicaps--such as mental retardation--may be known to professionals serving the individual, but have not been fully aggregated nationally for planning purposes."
> (Brewer & Kakalik, 1974, p. 19)

This statement is no less true today than it was when the Rand Corporation first published the Brewer and Kakalik reports in 1974. Despite the services provided and the advances made in the intervening decade, nationally aggregated data on the number and characteristics of deaf-blind persons in the United States are not significantly better or more extensive than ten years ago.

Then and now, the major source of information as to the total number of deaf-blind children has been Special Education Programs, U.S. Department of Education (SEP). These figures were reported periodically by Mr. Robert Dantona, for many years the federal official responsible for overseeing federal support for special education in the area of deaf-blindness. A quick review of a variety of special conference reports and journal publications on the subject of deaf-blindness during the

decade of the 70's and into the early 80's shows that Dantona's compilations represent the major national source of estimates of the size of the deaf-blind population through age 21. In addition to providing total numbers, the SEP data were frequently reported by state and region, as well as by age group. In some reports, the population was further classified as to whether or not the individuals involved were receiving special educational services in the regional deaf-blind centers or elsewhere, and according to the type of service being rendered. However, since the data reported by SEP are aggregate data on all deaf-blind persons in the region of each reporting center, only a limited amount of analysis is possible. The advantage of the SEP method is that the data approach completeness within their defined boundaries. For example, programs receiving federal funds for the support of regional or other programs for deaf-blind individuals were required to report these figures in the course of fulfilling their obligations as recipients of federal funds.

Even with that advantage, however, Brewer and Kaklik (1974) in their reports on federal support for special education in general, state their expectation that the total number of known deaf-blind individuals would rise in the years following their publication: "We feel that the 5,400 estimate for young persons is the most likely number, but a lower-bound would be the currently identified 4,400 and 7,000 would be an upper-bound unlikely to be exceeded without the creation of a comprehensive identification program for adults" (Brewer & Kakalik, 1974, p. 21). They were led to this wide range of estimates because of the limits of reliability of the sources they were using for population estimation. In 1980 Dantona reported SEP figures totaling 6,117 deaf-blind children to be served within all categories of educational programming (displayed graphically in Figure 1). This figure lies between the Brewer and Kakalik "most likely" figure of 5,400, and their upper-bound figure of 7,000.

The National Center for Health Statistics within the U.S. Public Health Service is responsible for producing national statistical information on health conditions throughout the United States. Their 1977 report indicated national estimates of self-reported visual impairments and hearing impairments, as shown in Table 1. As this table clearly shows, both visual problems and hearing impairments are quite widespread in the United States population, with over 11,000,000 individuals estimated to have some level of visual impairment and over 16,000,000 individuals estimated as having some degree of hearing impairment. Unfortunately, however, the way the National Center for Health Statistics collects, reports, and analyzes its data does not make it possible to obtain from their information the number of individuals with combined hearing and visual problems.

FIGURE 1. TOTAL NUMBER OF DEAF-BLIND CHILDREN BY AGE DISTRIBUTION
FEBRUARY 1980

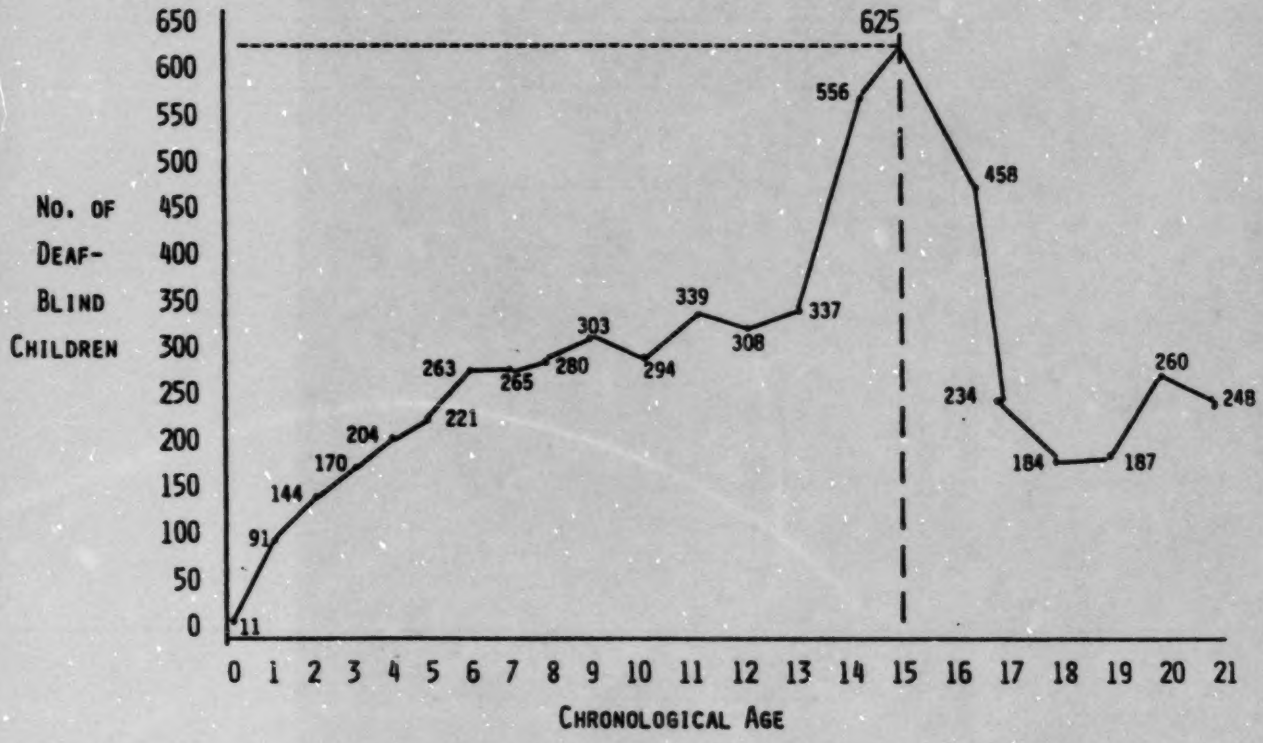

FIGURE 1

SOURCE OF DATA -- OFFICE OF SPECIAL EDUCATION (MR. ROBERT DANTONA)

TABLE 1. PREVALENCE OF SELECTED IMPAIRMENTS AND CHRONIC CONDITIONS REPORTED IN HEALTH INTERVIEWS, BY AGE: UNITED STATES CIVILIAN NON-INSTITUTIONAL POPULATION, 1977.*

Condition	All Ages	Under 17	17-44	45-64	65+	All Ages	Under 17	17-44	45-64	65+
	Number in Thousands					Prevalence Per 100 Persons				
Visual impairments	11,415	678	2,877	2,959	4,902	5.4	1.1	3.3	6.8	22.0
Unable to read newsprint with corrective lenses	1,391	37	105	259	990	0.7	0.1	0.1	0.6	4.4
Other visual impairments	10,024	641	2,772	2,699	3,911	4.7	1.1	3.2	6.2	17.6
Hearing Impairments	16,219	856	3,480	5,365	6,518	7.6	1.4	4.0	12.4	29.3
Population used in computing rates:	212,153	59,909	86,620	43,357	22,266					

*National Center for Health Statistics, Health Resources Administration, Public Health Service, U.S. Department of Health, Education, and Welfare.

Another approach to the problem of the size and characteristics of the deaf-blind population in the United States has been taken by the Demographic Studies Program at the Gallaudet Research Institute. This program was initiated in 1966 as a pilot program. After two years of field testing in the five state area surrounding Washington, DC, additional federal funds were authorized in 1968 to establish a national survey of hearing impaired children and youth; this has been conducted annually since that time. Participation in the study is entirely voluntary. The initial title of the federal grant was the "Model Reporting Area," indicating the federal intention at that time to use this statistical agency with respect to hearing impaired children as a model for similar services to be established in other fields of handicap and special eduation. Those future studies, however, were never in fact established.

The basis of this survey is individual child data, rather than figures aggregated on a program by program basis. Each participating educational program is asked to complete a data form for each child enrolled in their program; this information is then augmented and updated periodically. The resulting database has expanded slowly over the years, to its present size of approximately 55,000 hearing impaired children and youth throughout the United States. Because of the way the data is collected and maintained in the database, it is possible to do extensive analysis of the characteristics of the entire group and of various subgroups within the national sample. The limitation of the approach is that its voluntary nature and the fact that it requires considerable effort on the part of cooperating institutions produces a consistent bias in the direction of non-reporting or incomplete reporting.

Despite these limitations, the absolute size of the database has insured excellent stability in the figures from year to year. This, of course, greatly enhances its value.

At the present time, the Gallaudet Demographics Studies Program consists of approximately 1,500 "reporting sources," that is, sources which provide educational services to hearing impaired children and youth and which report information to the survey. The rather ambiguous term "reporting source" is used because of the great variability in the sources which report data. At one extreme, a source can be a particular private residential school for the deaf with less than 100 students or a small mainstream program in a rural area serving only 4 or 5 hearing impaired children. At the other extreme, a reporting source might be a major city school district, which serves tens of thousands of children all together, including thousands of children in special education programs and hundreds in programs for hearing impaired children.

Definition problems are a constant of any statistical or survey operation of this nature. Over the years this survey has refined its definition of "appropriate participating program" to any entity which provides special education or related services specifically intended for hearing impaired children or youth.

The extent and quality of coverage for deaf-blind children or, more broadly, for children with combined disabilities of hearing impairment and visual impairment is less well known. The survey's list of reporting sources includes a considerable number (approximately 12) of schools for the blind, schools for multiply handicapped children, and special units for hearing impaired children within such institutions or within state schools and hospitals for the mentally retarded. As a generality, if such an entity (say, a state school for the mentally retarded) considers itself as having a special program for residents who are hearing impaired, it is likely to participate in the survey. By contrast, if a similar institution has some hearing impaired residents but does not consider itself to have a specific program for them, it is less likely to participate.

The most recent complete survey is that for the 1983-84 academic year. A total of 55,136 hearing impaired children and youth were surveyed and, of this number, 3,231 (5.9%) were reported as having the combined disabilities of hearing impairment and visual impairment. Of this number, 1,085 (or 2.0% of the national total) were reported as having significant visual impairments but of a nature or severity less than required for designation of legal blindness. The Gallaudet survey, therefore, still includes only half as many deaf-blind children as were reported by Dantona in 1980.

The remainder of this paper will draw upon an analysis of individuals included in the 1983-84 survey as well as upon two other data sources. The additional data sources are surveys of the sensory impaired (hearing impaired, visually impaired, and the combination) conducted in the states of Louisiana and Nebraska by the same Gallaudet Demographics Studies Program under the auspices of the State Department of Education in the two states. It is important to note that the results from these two states are included in the national survey reported here.

The Nebraska survey of sensory impaired children and youth for the 1983-84 school year included a total of 884 children. Of this number, 94 (10.6%) had combined disabilities of hearing impairment and visual impairment. In the Louisiana survey, a total of 2,154 children were reported as having sensory impairments. Of this number, 209 (9.7%) were reported as having combined hearing and visual impairments.

Tables 2, 3, and 4 present highlights of some particularly relevant information from the national, the Nebraska, and the Louisiana surveys. The gender distribution nationally closely follows that for hearing impaired children, while the two state surveys show an even more heavily male population. The national distribution of racial/ethnic backgrounds for hearing impaired children does not exactly parallel that reported here for those with combined hearing and visual impairments (HI-VI). In particular, the HI-VI has a higher percentage of black students (22% versus 18%) and lower proportions of Hispanic students and those from other ethnic backgrounds than is the case for the hearing impaired student

TABLE 2: PERCENTAGE DISTRIBUTION OF SELECTED CHARACTERISTICS OF STUDENTS WITH COMBINED HEARING AND VISION IMPAIRMENTS: UNITED STATES, NEBRASKA, AND LOUISIANA, 1983-84.

	U.S. National			Nebraska	Louisiana
	Deaf & Legally Blind	Deaf with Severe Visual Impairment	Combined HI-VI	Combined HI-VI	Combined HI-VI
Number Located	1,085	2,146	3,231	94	209
Gender					
% Male	54	53	53	63	58
Racial/Ethnic Background					
% White	65	68	67	90	59
% Black	25	21	22	2	39
% Hispanic	8	9	9	3	*
Age at Onset of Hearing Loss					
% with onset before age 3	98	97	97	93	97
Characteristics of Hearing Loss					
% with severe-profound loss	68	71	70	42	61
% who use hearing aid	55	72	66	26	35

TABLE 3. PERCENTAGE DISTRIBUTION OF SELECTED CAUSES OF HEARING LOSS AND TERTIARY HANDICAPPING CONDITIONS OF STUDENTS WITH COMBINED HEARING AND VISION IMPAIRMENTS: UNITED STATES, NEBRASKA, AND LOUISIANA, 1983-84.

	U.S. National			Nebraska	Louisiana
	Deaf & Legally Blind	Deaf with Severe Visual Impairment	Combined HI-VI	Combined HI-VI	Combined HI-VI
Number located	1,085	2,146	3,231	94	209
Cause of hearing loss					
% maternal rubella	56	34	41	9	34
% heredity	4	8	7	4	10
% complications of prematurity	6	8	7	3	4
Tertiary Handicapping Conditions*					
% mental retardation	55	24	34	48	45
% brain damage	17	9	12	28	--
% emotion/behavioral disorders	15	12	13	15	5
% heart disorders	13	12	12	9	3
% orthopedic impairments	12	11	11	46	9
% other health impairments	9	12	11	19	7
% cerebral palsy	8	9	9	40	10
% epilepsy/seizure disorder	8	5	6	40	3
% other specific learning disabilities	5	10	8	5	5

*Note: percentages may add to more than 100% because more than one tertiary handicapping condition is reported for many students.

population. Nearly all of the youngsters with combined HI-VI had an onset of hearing loss before age three, i.e., before the normal development of spoken language. On the national level, more than two-thirds of the students have hearing losses in the severe to profound range (a loss of 71 Db or more in the better ear), and an approximately comparable proportion wear hearing aids. These figures differ considerably, however, in the two state surveys.

Far and away the most frequently reported cause of hearing loss (and in this case, presumably of the visual impairment as well) is maternal rubella. This pattern holds for the nation as a whole and in Louisiana, but does not appear to hold for Nebraska. The next most frequently reported causes of hearing loss in all three studies were heredity and complications resulting from prematurity. Half or more of these students with combined hearing and visual impairments are also reported to have one or more tertiary handicapping conditions. By far the most commonly reported tertiary handicapping condition is mental retardation. Very considerable proportions of the HI-VI population are also reported to have the other tertiary handicapping conditions listed in Table 3. In all cases, the rates of tertiary handicapping conditions reported for HI-VI children are higher than the rates for the same conditions reported as secondary handicapping conditions for children in the national annual survey of the hearing impaired children and youth.

Table 4 reports information on program location and communication services available to HI-VI youngsters. The proportion of HI-VI students who reside at their school approaches 40%, or more than double the rate of residential placement for youngsters with hearing impairments alone. Particularly interesting is that a minority of HI-VI children are mainstreamed with hearing students, a proportion which varies from 1/5 to 1/3 in the various subgroups. Of particular note is the finding that 45% of mainstreamed students who are both deaf and legally blind are provided with no additional support services in the mainstream setting. Only 1/4 to 1/3 of these children, at best, are provided with an interpreter, and only very small percentages have available to them the services of a note-taker. The most commonly provided support service is a tutor, which appears to be available to approximately 1/3 of these children on a national scale. All of these patterns, as can be seen from the Table, vary considerably in the two states.

As to communication approaches, approximately 3/4 of HI-VI students nationally receive speech and auditory training, and a comparable number are provided with sign language communication in their school programs. However, only a small percentage also have home environments in which sign communication is used.

Several points are particularly important as an overall summary. First, maternal rubella is by far the most common cause of the combination of hearing and visual impairments in school age children throughout the

TABLE 4. SELECTED PROGRAM CHARACTERISTICS OF STUDENTS WITH COMBINED HEARING AND VISION IMPAIRMENTS: PERCENTAGE DISTRIBUTION, UNITED STATES, NEBRASKA, AND LOUISIANA, 1983-84.

	U.S. National			Nebraska	Louisiana
	Deaf & Legally Blind	Deaf with Severe Visual Impairment	Combined HI-VI	Combined HI-VI	Combined HI-VI
Number located	1,085	2,146	3,231	94	209
Program Location*					
% in a program for hearing impaired students	19	61	47	9	41
% in a program for multiply handicapped hearing impaired students	51	30	37	46	13
% in other types of programs	41	19	26	31	32
% in a residental school for deaf students	14	31	25	--	--
% who reside at their school	53	31	39	39	54
% mainstreamed with hearing students	27	36	33	21	18
-% with NO support services	45	29	33	7	38
-% with interpreter	18	32	28	6	39
-% with notetaker	5	5	5	11	11
-% with tutor	28	33	31	17	17
Communication Services*					
% who receive speech and auditory training	73	78	76	55	--
% of students who use signs	63	76	72	--	57
% whose school program uses signs	73	78	76	--	--
% whose home environment uses signs	49	41	44	--	--

Legend: "--" indicates that the particular data item was not collected in the survey in question.

*Note: percentages may add to more than 100% because more than one program or service type is reported for many students.

United States. Children with this dual disability, especially those whose disabilities resulted from maternal rubella, are very likely to have one or more tertiary handicapping conditions on top of the dual sensory disability. Chief among these is mental retardation. This is, therefore, an extremely severely impaired group, more severely impaired even than the combination of hearing and visual impairments alone would suggest. Finally, while a majority of HI-VI youngsters are in special schools or programs, approximately 20%, also have all or part of their academic program in a mainstream setting with hearing children. Of those who do participate in such mainstream settings, nearly half do so without any additional supportive services provided in consideration of their multiple disabilities.

POPULATION STUDIES IN DEAF-BLINDNESS: CURRENT STATUS AND FUTURE DIRECTIONS

The first portion of this paper has focused upon the available sources of demographic and population characteristics information on the HI-VI population, and has presented a capsule picture of this population as seen through the available studies. The remaining portion will analyze and critique the "state-of-the-art" in population and demographic studies for this group of people, and will recommend several directions for future work.

Both major data sources reported here, namely, the SEP figures reported periodically by Mr. Dantona, and the findings from the Gallaudet Research Institute's Annual Survey of Hearing Impaired Children and Youth are focused only on the school age population. Extremely limited data is available above the age of 21. Beyond this, each of the two major sources suffers from a major limitation. The figures are reported to SEP by the service programs on a case-by-case basis but reported by SEP in aggregate form. While such figures can provide regional and national totals, cross-tabulation analysis and recombination of the data is very difficult when collected this way. The Annual Survey data is substantially superior on this count, since that database is assembled on a case by case basis, and therefore allows great latitude for cross-tabulations, combinations, and other more sophisticated analysis of the available data.

The Annual Survey suffers, however, in its coverage in several respects. First, since it is a strictly voluntary system, not all existing programs choose to report data to the survey (nationally, approximately one-fourth of the invited programs declined to participate). In addition, specifically with respect to combined hearing and vision impairments, not all programs which provide special educational services to HI-VI or deaf-blind students know of or are known to this survey. This is a natural consequence of the way in which the Annual Survey program was developed, namely, as a system for collecting information about hearing impaired children. The implications of this program coverage problem can be seen by comparing the national figures with those in the two states reported,

where coverage is far more nearly complete and where the formal authority of the State Department of Education rests behind the survey project. In the states, approximately 10% of all children reported to the survey have combined hearing and vision impairments; this compares to just under 6% in the national survey. While it is a bit risky to extrapolate from two states only, these figures suggest that the national survey is capturing only a bit over half of the national HI-VI population. The same conclusion is reached by comparing the HI-VI totals in the Annual Survey with the number of deaf-blind children reported in the most recent figures from the Special Education Program.

It is clear, then, that improvement of demographic and population characteristics data for the future will require at least two major conditions: first, that the coverage of such studies span the entire age range and not be limited to school age children; and second, that the agency conducting the study develop the broadest possible coverage of service programs where deaf-blind or HI-VI individuals might be located. The development of any such study, of course, immediately raises definitional questions. In this case, the most elementary form of the question is whether such a study should focus strictly on deaf-blind individuals or more broadly on those with combined hearing impairments and visual impairments. From a population study perspective, the answer to this is very clear: the broadest possible coverage should be sought for the studies, including collection of sufficient data on the nature and extent of both the hearing and the visual impairments that the resulting study population can be appropriately described, and if desired, analyzed in various subcategories. To limit survey coverage through excessively restrictive definitions will simply increase the difficulty of the study and decrease the eventual value of its findings.

Another important consideration is that of the general methodology of such a study. In particular, the issue relates to the collection of data on an individual case by case basis, as opposed to collection of already aggregated data from service agencies. As stated previously, further aggregation of data reported initially in already aggregated form adequately serves the purpose of head-counting and some elementary description of the population, such as the gender ratio or the ethnic distribution of the population. Such aggregated data, however, cannot be further analyzed or subdivided and cannot, therefore, be used to answer such additional questions as whether the distribution of etiologies or tertiary handicapping conditions vary according to gender, ethnic background, age, and other relevant characteristics. For such questions to be answered, and for general power and flexibility in being able to recast the data to answer questions developed in the future, it is necessary to collect information on an individual case by case basis. If all that is desired at the national level is a series of simple aggregations, the purpose can be served by establishing a variety of state registries or regional registries of deaf-blind persons. Aggregate data collected by such registries can then be amalgamated into national counts for the

limited purposes described above. However, while it is theorically possible for 50 states plus the associated territories each to conduct a case by case study of their populations in such a way as to permit later compilation of a national data file, in practice this would render a national compilation almost impossible. Only the direct national compilation of case by case data by a single research agency can adequately develop the databases required for the extensive demographic and population characteristics research which has been called for in the literature and by the planning committee for this research priorities conference. General methods and procedures for doing this have already been well developed by the Demographic Studies Program of the Gallaudet Research Institute and these could be adapted to studies of the present population of interest.

That same national survey, as well as the various state surveys associated with it, has shown that there is also great value in the repetitive and cumulative nature of such an activity carried on repeatedly over time. Inevitably, the service programs from which individual client data must be obtained will not have available all of the requisite information at the time a one-time-only national study might be undertaken. Periodic repetitions of the study, whether at annual, biannual or other intervals, are necessary to improve the quality of the original data sources as well as the resulting national compilation. In addition, a repetitive study of this sort offers the possibility, over time, of accumulating a much larger and more powerful database than could possibly be gathered at any one point in time. The amount of time and effort available at the individual program level or at the research study agency level is limited at any given time. However, if additional items of relevance are asked in each subsequent survey after the first, it is possible to assemble an increasingly more sophisticated database without requiring untenable levels of effort and expenditure in any one year.

Another major consideration is that the particular data items to be collected in such studies should be carefully reviewed and agreed upon by representative professionals and consumers from across the country, in order to ensure that the answers eventually developed by the population study program respond to real questions on the part of service providers and funding agencies. This, in addition to basic descriptive characteristics of the individual and his/her disabilities, the data collection can include for example, such considerations as legal eligibility for a variety of programs, descriptions of services needed and/or being received, and progress over time on any of a variety of measures.

Studies of this sort, particularly if they are planned as a continuing series as suggested here, require a considerable investment of time, money, personnel, and other resources. They also require extended periods of planning and development to ensure the adequacy of the data collection forms and procedures, and their acceptability to the service agencies

which must later cooperate in providing the required information to the study office. Any proposed activity in this direction should also be planned with full awareness of the existing activities of various state and federal agencies in collecting administratively required data, and also with full awareness of the extensive data alreay being collected on part of this population by the Gallaudet Research Institute Demographic Studies Program. While all legislative and government officials look for population information in making planning and budgeting decisions, it is difficult to obtain the funding to develop the necessary statistical data in the first place. Therefore, it is extremely important that the planning and decision making for any expanded or improved population studies in the area of deaf-blindness be well and carefully thought out, since it would be difficult to obtain future funding for work in this area if earlier efforts were attempted but inadequately implemented.

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CHAPTER 2

RESEARCH PRIORITIES IN DEAF-BLIND REHABILITATION: DEMOGRAPHIC CHARACTERISTICS OF THE POPULATION

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The planning, development and delivery of meaningful rehabilitation and related services to deaf-blind individuals and their families challenges the creative imagination and energies of the human services community. The character of this disability is highly individualized, making it difficult for service providers to define, identify and describe the target population to be served. Rehabilitation and related human service program efforts on behalf of deaf-blind persons need a mechanism through which to plan and provide services to deaf-blind clients. The kind of planning information system that is essential for the cost-effective delivery of meaningful services could best be achieved by the establishment of a national, centralized consortium.

RECOMMENDATIONS FOR A DEMOGRAPHIC STUDIES CONSORTIUM IN DEAF-BLINDNESS

A necessary prerequisite for federal, state, and local planning and monitoring of services to deaf-blind persons is the availability of a wide variety of demographic and other descriptive data on the life situation, status, accomplishments, and needs of deaf-blind persons. Therefore, the members of Core Area Group 1 recommend that The National Institute for Handicapped Research support the establishment of a continuing demographic and population studies program within some appropriate agency or institution which is committed to demographic and population studies of persons with sensory impairments.

The consortium would solicit data on a voluntary basis and would support at least the following sorts of projects, both by making use of its own resources and by coordinating with other appropriately related research groups.

1) An archives of information on deaf-blind persons, including a listing, description, and critique of existing data bases.

2) A directory, with descriptive information of programs, agencies, and institutions which provide education, rehabilitation, psychosocial, technological or other services to deaf-blind persons at any age.

3) National, regional, and local data on the characteristics, status, achievements, and needs of deaf-blind persons.

4) Information on recruitment, training/retraining, retention, and evaluation of service providers to the deaf-blind population, including interpreters, teachers, social workers, rehabilitation personnel, etc.

The Helen Keller National Center (HKNC) might serve as host institution for such a consortium. Parts of this research could be subcontracted to other research groups and centers. This would provide a major "boost" to research in deaf-blindness in a cost-effective manner.

RECOMMENDATION FOR NIHR LEADERSHIP ON THE FEDERAL LEVEL

The National Institute on Handicapped Research is requested to utilize its leadership role within the federal system and within the Interagency Committee on the Handicapped:

1) to work with federal agencies which collect data such as the Congressional Research Center, the Department of Labor, the Department of Education, the National Center for Health Statistics, the Rehabilitation Services Administration, the Administration on Aging, and the U.S. Census Bureau, to add specific questions and/or coding categories concerning deaf-blindness, hearing impairments, and visual impairments to their usual data gathering instruments;

2) to encourage other federal agencies to sponsor research on deaf-blindness, visual and hearing impairments as appropriate to their mandates;

3) to urge other federal agencies to provide additional services for deaf-blind, hearing-impaired and visually-impaired persons;

4) to act as the interface between the Demographic Studies Consortium in Deaf-Blindness and other federal agencies collecting data, supporting research and providing services to deaf-blind, visually-impaired and hearing-impaired persons;

5) to encourage and assist the Rehabilitation Services Administration and state vocational rehabilitation agencies to push forward in their implementation of specific coding of deaf-blind cases.

RECOMMENDATIONS FOR 22 SPECIFIC RESEARCH PROJECTS

Prior to the conference a national survey was mailed to leaders in the field requesting their priorities for specific research efforts they would recommend be undertaken related to demographic and population characteristics. A total of 77 specific research projects were recommended by 38 respondents for this priority area. A content analysis reduced the original pool of 77 to 22 unduplicated recommendations which were then reviewed by the Core Area Group I during the November 2-5, 1984 National Conference. Members of the Core Area Group I team recommended that the 22 field-initiated recommendations for specific research projects be submitted to NIHR as priorities for demographic research in deaf-blindness.

THREE MAJOR TYPES OF RECOMMENDATIONS

Table 1 summarizes the three major types of research projects that are recommended.

TABLE 1

Types of Recomendations Made for Demographic Research Projects

Types of Recommendations Submitted	No. of Unduplicated Projects Recommended	No. of Recommendations for Type of Research
All Recommendations	22	77
A. Census /Description	8	26
B. Definitions/Eligibility	3	14
C. Service Delivery Issues	11	37

While each of the 22 recommended actions for specific research projects merits consideration, the following sections summarize the recommendations submitted by the members of the Core Area Group 1.

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A. CENSUS AND DESCRIPTIVE RESEARCH

Table 2 presents specific projects that are recommended for priority consideration in census and descriptive research.

TABLE 2

Eight Specific Census and Descriptive Research Projects Proposed by 26 Respondents
N=26

Number of Respondents Recommended Project	8 Specific Research Projects Proposed
11	A National Census of the Deaf-Blind Population
4	A State-by-State Registry of Deaf-Blind Persons
3	Population Changes Over the Years
3	Research on Causes of Deaf-Blindness and Restoration of Vision and Hearing
2	National RSA-300 Coding of Deaf-Blindness for Studies of VR Services
1	Methodology for Local Census Studies
1	Distribution of Minorities and Minority Cultures
1	Types of Employment

Priority Statements. The 26 recommendations submitted under this heading fall into 8 categories that deal with census and descriptive research projects. Because of limitations of space, only the first three priority statements are outlined below.

A-1 A National Census of the Deaf-Blind Population (11 recommendations). This priority calls for a national census of the deaf-blind population in the U.S. The primary intent is for research to provide definitive information about the size, distribution and salient characteristics of deaf-blind persons in order to better plan and provide services to these individuals.

A-2 A State-by-State Registry of Deaf-Blind Persons (4 recommendations). A closely related priority is for research efforts to develop and then maintain a state-by-state registry which will contain descriptive information on all deaf-blind residents of each of the 50 states. Two primary goals are: (1) to construct a "model" state registry and assist the states to implement one themselves, and (2) to utilize the state registry data bases for various research studies as needed to guide state, regional and national program planning and development efforts.

A-3 Population Changes Over the Years (3 recommendations). Noting that dramatic changes have occurred in the numbers, characteristics, and services needs of deaf-blind persons during the past 10 years, several respondents recommended that research be undertaken to identify those client changes and assess how service programs, techniques and procedures need to be adapted in order to accommodate changes in the client population.

B. DEFINITION/ELIGIBILITY DETERMINATION

Table 3 presents a summary of the specific projects that are recommended for research related to definition and eligibility.

TABLE 3

Three Specific Definition and Eligibility Research Projects Proposed by 14 Respondents
N=14

No. of Respondents Recommending	3 Specific Research Projects Proposed
8	Functional Definition of Deaf-Blindness
3	Potential to Benefit from VR Services
3	Which Agency More Effective in VR Service to Deaf-Blind Persons

Priority Statements. The 14 recommendations submitted for this priority, address three specific research recommendations.

B-1 Functional Definition of Deaf-Blindness (8 recommendations). A legal and/or functional definition of who is deaf-blind is a necessary prerequisite to identifying and serving these individuals.

B-2 Potential to Benefit from VR Services (3 recommendations). A closely related priority was for research projects that would analyze the characteristics of those deaf-blind persons who (a) do benefit, or (b) do not benefit from VR services. The issue is how better to structure and monitor the criteria for determining eligibility for VR services.

B-3 Agency Effectiveness in Providing VR Services to Deaf-Blind Persons (3 recommendations). This priority addressed the need for research to ascertain whether (a) the general VR agency, (b) the VR agency for the blind, or (c) the special services (e.g., Deaf-Blind services) program within the state agency can best serve the VR needs of the deaf-blind clients.

C. SERVICE DELIVERY ISSUES

Table 4 presents the specific projects that are recommended for consideration in establishing priorities for research related to service delivery.

TABLE 4

Eleven Specific Service Delivery Research Projects
Proposed by 37 Respondents
N=37

No. of Respondents Recommended	11 Specific Research Projects Proposed
8	Casefinding Systems
6	Effective VR Services & Techniques
6	Skills and Knowledge of Service Providers
4	Development of Diagnostic Tools and Procedures
3	Range and Nature of Services Needed
2	Networking and Interagency Coordination
2	Impact of Funding Incentives
2	Service Alternatives for Severely and Multihandicapped Clients
2	Retraining of Usher's Syndrome Clients
1	Alternative Housing Needs
1	Impact of "Functional" Deaf-Blindness on the Service Delivery System

Priority Statements. The 37 specific recommendations are summarized in 11 service delivery priority statements. Because of space limitations, only 3 are listed below.

C-1 Casefinding Systems (8 recommendations). Recommendations for this priority focused on research and demonstration of model systems designed to locate and identify specific groups of deaf-blind persons who are (a) children, (b) persons with Usher's Syndrome, (c) ethnic minorities, (d) living in rural areas, and (e) elderly persons with late-onset of deaf-blindness.

C-2 Effective VR Services and Techniques (6 recommendations). Research is needed to identify rehabilitation techniques, interventions, and procedures that prove effective in use with deaf-blind persons. One example is an analysis of job placement techniques that are effective in the placement of deaf-blind persons in competitive employment.

C-3 Skills and Knowledge of Service Providers (6 recommendations). Research into the communication, counseling, and related skills and knowledge is needed for effective VR case management with deaf-blind persons.

RANK-ORDER OF THE 22 RESEARCH PRIORITIES

Table 5 presents a rank-ordering of the 22 research projects in terms of their priority, irrespective of the type or category of recommendation. The ranking of a particular recommendation is based on the frequency by which a specific project was nominated as a priority activity.

TABLE 5

Rank-Order of Specific Research Projects:
Ranking by Frequency of Recommendations

Rank-Order	Number of Respondents Who Recommended the Project	Title of the 22 Specific Research Projects Recommended
1	11	A National Census of the Deaf-Blind Population
2	8	Functional Definition of Deaf-Blindness

TABLE 5 (cont'd)

Rank-Order	Number of Respondents who Recommended the Project	Title of the 22 Specific Research Projects Recommended
2	8	Casefinding Systems
3	6	Effective VR Services and Techniques
3	6	Skills and Knowledge of Service Providers
4	4	A State-by-State Registry of Deaf-Blind Persons
4	4	Development of Diagnostic Tools and Procedures
5	3	Population Changes over the Years
5	3	Research on Causes of Deaf-Blindness and Restoration of Vision and Hearing
5	3	Range and Nature of Services Needed
5	3	Potential to Benefit from VR Services
5	3	Which Agency More Effective in VR Service to Deaf-Blind Persons
6	2	National RSA-300 Coding of Deaf-Blindness for Studies of VR Services
6	2	Networking and Interagency Coordination
6	2	Impact of Funding Incentives

TABLE 5 (cont'd)

Rank-Order	Number of Respondents who Recommended the Project	Title of the 22 Specific Research Projects Recommended
6	2	Service Alternatives for Severely and Multiply-Handicapped Clients
6	2	Retraining of Usher's Syndrome Clients
7	1	Methodology for Local Census Studies
7	1	Distribution of Minorities and Minority Cultures
7	1	Types of Employment
7	1	Alternative Housing Needs
7	1	Impact of "Functional" Deaf-Blindness on the Service Delivery System

CHAPTER 3

PSYCHOLOGICAL, DEVELOPMENTAL, AND MENTAL HEALTH ISSUES OF DEAF-BLINDNESS

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INTRODUCTION

The purpose of this paper is to identify and review some of the more significant publications relating to developmental and mental health issues affecting the deaf-blind population. There is a paucity of literature in these areas, particularly that which reports results of data-based research. Most of the research is relatively recent. Printed proceedings of meetings such as one held in Boston, Massachusetts, under the sponsorship of the Mid-Atlantic-North and Caribbean Region Center for Services to Deaf-Blind Children (Wolf, 1980), contain the best available summaries of research completed and in progress. Reports of this nature, along with scattered journal articles, constitute the bulk of the recorded body of knowledge related to research on deaf-blindness.

HISTORICAL PERSPECTIVE

During an 18-month period between late 1963 and early 1965 an epidemic of rubella moved through the United States resulting in the birth of thousands of affected children. Of this group, some 3,000 infants were congenitally deaf-blind. In addition, many of them have additional handicaps of a severe nature. This epidemic was so overwhelming to families, the professional community, and others who were engaged in planning and providing support services to the handicapped population that the federal government was persuaded to intervene. In 1968 a public law was passed in the United States Congress to provide support to this population. The legislation was a landmark in the sense that it was intended to provide a significant amount of the diagnostic and educational services needed by the rubella-handicapped population. This was in contrast to the usual federal role of providing a relatively small portion of funding necessary for the education of a particular group or population segment. Although it was the rubella epidemic which led to the provision of support from the federal government for centers and services for deaf-blind children, these centers also have been instrumental in identifying and serving more than 3,000 individuals who are deaf-blind due

to genetic syndromes and other causes in addition to rubella. Prior to this time, services were either nonexistent or very fragmented for deaf-blind persons. Historically, programming for deaf-blind children was centered in two or three schools and rehabilitation programs. Notable among these is Perkins School for the Blind which has served a significant number of young deaf-blind students, and the Industrial Home for the Blind which has served a number of deaf-blind adults. As greater attention was placed on programs and services for the young deaf-blind population, it followed that increasing numbers of adults were being identified as unserved and, accordingly, services were expanded to meet at least some of the needs of this growing population.

Other programs across the country have been established as models and for demonstration. Funds from federal laws other than the Deaf-Blind Act, e.g., the Rehabilitation Act of 1973 as well as the 1974 and 1978 amendments to this Act, have provided additional funds for programs benefitting deaf-blind persons.

More recently there has been some indication of a shift in public policy on the part of the federal government: specifically, an attempt to encourage states and other jurisdictions to assume a greater share of responsibility for the needs of handicapped persons. This shift has been noted for a number of years. Das (1980) reports,

> "...with the passing and implementing of Public Law 94-142 in 1975, the federal government is altering serice commitments in a substantive way, that is, transferring responsibility to the states and that in all probability funds will neither be adequate nor will they reach deaf-blind programs to the extent they do at present."

The potential for impact of this conference is heightened by the possibility of further public policy change in the direction noted above. A major objective of the conference is that of identifying those service areas and associated research needs which will help ensure that current levels of support and service to the deaf-blind population are maintained. This conference, therefore, has the potential to provide strong influence on the direction of programming, research, and other services provided to this population by state and local jurisdictions.

DIVERSITY OF THE DEAF-BLIND POPULATION

The handicapped population often is viewed either as a single class with common needs, or, similarly, as a set of categorical classes; yet the

population is more diverse in both needs and abilities than is the remainder of the general population. This is particularly true of the deaf-blind population. While the majority of deaf-blind persons has additional handicaps such that the prognosis for significant educational achievement and the gaining of independence must be guarded, there are many persons within this population who have great potential. It may be useful, therefore, to discuss briefly some of the characteristics of the population which lead to this wide range of variance. It is helpful to review some of the major etiologies of deaf-blindness, to consider the prognosis for development related to certain etiologies, and to consider other statistics related to etiological demographics.

The 1979-80 demographic profile of 6,117 deaf-blind children known to be served in educational programs in the United States suggested that less than 1/2 are deaf-blind due to maternal rubella (Wolf, 1980). One could conclude that over 3,000 individuals between the age of 0-21 and an estimated 15,000 adults in the United States are deaf-blind because of one of three categories of etiology: genetic, prenatal infectious diseases other than maternal rubella, or postnatal acquired disease/trauma. Usher's Syndrome is the most common disorder among adults who are deaf-blind. Vernon (1969a; 1969b) reports that as many as half of those persons identified as deaf-blind during adulthood are due to Usher's Syndrome. Konigsmark and Gorlin (1976) discussed 25 syndromes which have deafness and eye disease as associated characteristics. (See Appendices for tabular differentiations between some of the characteristics of deaf-blindness acquired through congenital infectious disease and characteristics of deaf-blindness acquired postnatally through other disease or trauma. These indicate that loss in the two sensory modalities (hearing-vision) is:

1. progressive in nature for both senses in 25 causes;
2. progressive in one modality, usually vision, with a stable loss in the other, in 6 causes;
3. non-progressive in the 6 remaining causes.

Usually congenitally infectious and postnatally acquired deaf-blindness are not progressive in nature; however, more than 69% of all genetic-linked dual losses are progressive in nature.

The psychological impact of dual progressive loss in vision and hearing is especially traumatic and deserves research attention. Vernon (1969a) concluded that deaf-blindness is one of the most psychologically devastating events known to humans. The reaction to sudden or progressive sensory losses can be compared to the "loss model" or "grief work" as described by Hicks (1978), as well as "stages of dying" as described by Thibadeau (1981). The gradual process of gaining knowledge and understanding with regard to the nature of such sensory losses is crucial to the adjustment necessary to maintain stable life patterns. As

individuals go through the continual adjustment process they will also directly and indirectly influence and affect other persons in their lives. Much of the information on the psychological and mental health issues surrounding progressive losses in hearing and vision comes from persons who themselves have experienced this loss. It is their statements within the literature which are so important and necessary to an understanding of the impact of this life situation. For this reason, a number of such statements of individuals are presented here in an effort to help direct and shape the thinking of the conference group regarding needed research.

Arthur Roehrig (1980), a well-educated person who became deaf-blind gradually as a result of Usher's Syndrome, states; "The fact I became aware of my deteriorating vision through a gradual process enabled me to accept this handicap with less trauma than I may have experienced otherwise." Roehrig also noted later, "...deaf-blindness, with its problems of communication and mobility, can create a unique situation of isolation."

Robert Smithdas has become a model for many parents, professionals, and the persons with progressive hearing and vision loss. He has a very deep insight into their needs and emotions. The following statements are taken from several papers (e.g., 1975; 1977) he has written during the past few years; they speak for themselves and need no interpretation:

> "Of all groups of severely handicapped people, it is safe to state that the deaf-blind comprise a group of individuals who have most often been neglected and isolated by society. It is not unusual for deaf-blind individuals who have been isolated from social contacts for a prolonged period of time to develop patterns of behavior which are not acceptable to society in general. Temper tantrums, irresponsiveness to others, careless habits of personal hygiene and social behavior are just a few of the mechanisms which may be used for defense and self-protection. When these patterns become firmly entrenched, it may require a long period of rehabilitation training to re-establish acceptable modes of behavior."
>
> There is still urgent need to emphasize the fact that we have not found solutions to all the unique problems of communication, mobility and social adjustment which loss of sight and hearing produce.

Yoken (1979) interviewed and wrote about deaf-blind individuals across the United States. The following excerpts are quotes from some of those deaf-blind individuals participating in the interviews (with accompanying comments from the author.)

"When I get my vision back, I'll have friends. Oooh. Happy to see me. Probably wanna buy me a drink. They didn' worry about seein' me the 5 years I was deaf and blind. I don't call 'em friends; friends are hard to come by."

"Independent living for the handicapped can turn out to be very lonely. They end up in an apartment by themselves, a little less able to get out and contact people. I suppose that some people have found it's not all that it's cracked up to be. In general, Joan can communicate very well in one-to-one situations. In groups, however, she is left out. She has often found herself enjoying a conversation with a companion until a third person approaches; then they seem to forget her. She says it makes her feel like shouting, 'Talk to me!' but she continues, 'You can't fill yourself up with that all the time or you do even less communicating. You can't keep making pest out of yourself. So on some people, you just give up.'" Yoken feels communication remains Joan's biggest problem.

"I was really shocked. I couldn't believe it. I told the doctor, 'All this time and I didn't know. That was why I was so frustrated and unhappy.' After all those years. I don't know what it would have been like before if I'd known the problem better. I might have been the same, I don't know. But I was glad to find out. But it was also hard for me to believe the other stuff."

"When I was lay off, I go to Red Cross volunteers. But I cannot help. They say work with children or old people. I cannot--I cannot hear. I like to help with old people in hospital, help from bed, but I cannot; I don't have the strength. I like to make for doctors stick with cotton tips, but they have 10 people do that; that is all. I like to do office, but they have none. Work with blind, I try, ja, go two places. But I cannot hear. I don't want to sit home all day. I'm tired of it. I am too nervous. I go out to park, see people. If I were not blind and deaf, I would not work as keypunch. I could go to store as salesgirl. Salesgirl can be 80 years old. I go ask...be cashier. But no, I cannot hear. Now, if I work part time, lose Social Security, Medicare. Then I must pay high insurance. I pay already Blue Cross. More I cannot pay. Nothing can do now. No friends, no work. I do here needlepoint. For whom? I can nothing plan. If I have some friends, we can go somewhere. I have no me. Go to park, feed squirrel."

"Isolation, dependence, anger, and resentment are present in the lives of most of those interviewed, but for no one are they so all consuming to completely control and define the person.

> The individuals have remained individuals, largely through the process of adjustment to their losses and limitations. A person's adjustment depends in part on experiences before becoming a deaf-blind-personality; self-image, and feelings about disabilities in general or specifically deaf-blindness. Adjustment depends, too, on situations encountered as a deaf-blind person, including societal attitudes reflected in other people's behavior and the public policies that affect everyday experiences. The inevitable reduction in communication inherent in deaf-blindness has an inestimable impact on a person's life; input and exchange that are tremendously restricted can redirect an individual's experiences in unfathomable ways."

Yoken provides background information, including etiology, for each of her subjects. Regardless of etiology, however, the behavior pattern and attitude suggest that life for the deaf-blind person centers around interaction with other people. This is accomplished through communication. The psychological impact of isolation due to deaf-blindness is yet to be studied.

The needs of our present population of deaf-blind individuals are not unique. A review of the proceedings of conferences and seminars, which explored the needs of the deaf-blind population, indicates this need as paramount and unchanging.

REVIEW OF STUDIES AND SEMINARS

As reviewed in Wolf (1980), one of the earliest research projects focusing on deaf-blind persons was by Rocheleau and Mack in 1930. The study included 618 persons whom they estimated represented only one-fifth of the total deaf-blind population of the United States. Very few of these were reported to have achieved personal or professional independence. The 1956-58 study by the Industrial Home for the Blind (IHB) concluded that rehabilitation services could be effective for deaf-blind. The Anne Sullivan Macy Service for Deaf-Blind was established as a means of initiating such services.

In the preface to a report of an early seminar on research of deaf-blindness, conducted by the IHB with the support of the Vocational Rehabilitation Administration, Salmon (1966) states, "Research is the key to new knowledge in this field. As yet research has generated relatively no information concerning deaf-blindness."

During this seminar a review of 180 New York State cases by Joseph J. Parnicky (1966) revealed evidence that a significant number of individuals are not overwhelmed by deaf-blindness, or if they are, they are able to

rally their resources and establish a place for themselves in the community. He suggested the advisability of an intensive study of deaf-blind individuals living independently to identify better the techniques that enable them to move toward this achievement. This would enable teaching these techniques to help others make comparable progress.

During this seminar four major areas for research were explored: (1) communication, (2) learning, (3) rehabilitation and (4) resettlement. Rusalem (1966) stressed the crucial nature of communication for deaf-blind persons.

> "Communication is the Rosetta Stone of the rehabilitation of deaf-blind persons. If cut off from prolonged human contact, deaf-blind persons tend to behave erratically. For example, when deprived of interpersonal relationships and means of self-expression for protracted periods, they often tend to evidence withdrawal symptoms interspersed with episodes of highly volatile, sometimes violent behavior."

He further states, "Exploration is needed of the specific language structure and the implications of improved language for other areas of life function."

The 1966 seminiar was held two years after the maternal rubella epidemic.

The prolific growth of information during the next 18 years created a need for many workshops, conventions, seminars and conferences to discuss and share ideas related to deaf-blindness. Many of the issues centered around early intervention and learning behaviors of the maternal rubella deaf-blinded population.

Service providers have suggested that adult deaf-blind people utilize unique learning styles (Hammer, 1980). Studies on young children do also suggest some unusual learning styles but additional research is essential to address this hypothesis for youths and adults who have established their learning style long before deaf-blindness.

Studies on service delivery for the deaf-blind have historically used principles proven effective with other populations. The major reason for this practice was the diagnosis of thousands of deaf-blind "at risk" infants during a three-year period. Proven methods and the teaching of trained professionals were nonexistent. This population did not have the luxury of previous years of study, nor did they have the time to wait for such studies. Today both methods and trained professionals wait to be studied for the next major stage of growth of deaf-blind individuals.

Appell (1980) stresses the need for research to establish the progress of deaf-blind persons as they go through Epstein's five growth

stages: 3-10 months of age; 2-4 years; 6-8 years; 8-12 or 13; and 14-16 or 17 years. The majority of the deaf-blind have matured through four growth stages. How does their growth compare to the nonhandicapped learners?

Study of the vast amount of data collected during the growth of this population could provide a strong basis for the next stage of growth.

Hammer (1980) suggests that children with congential rubella syndrome (CRS) may have a "longer growing season;" he cites Murdina Desmond of the Baylor Rubella Study Group C who found that the nervous system in this group of deaf-blind persons keeps changing (and progressing) up to the third decade of life. It is important to track this maturation and to insure a full range of services to assist in the completion of potential development.

Maternal rubella yielded a deafened population with distinctive demographic characteristics. It appears that the deafness caused by maternal rubella can be more severe than for the other causes taken as a whole (Brown & Karchmer, 1984). Blindness or visual problems are roughly 15% for CRS adolescents as opposed to 4% for other youth with hearing losses. It also appears that the CRS youth are more likely than other deaf children to suffer from two congnitive learning handicaps: emotional/behavioral problems and mental retardation.

Shaver and Hicks (1984) report the occurrence of late onset problems in persons with CRS including vascular disease, thyroid problems, and diabetes mellitus. Their study found two percent of the students with CRS had overt, undiagnosed diabetes and almost 20% of these students had abnormalities indicative of a possible pre-diabetes state. The rapid onset and severity of the diabetes most often found in children and young adults with CRS could potentially alter their behaviors if untreated.

The emotional/behavioral problems found among the CRS youth need to be monitored, and methods of intervention shared among professionals working with this population. Additional handicaps, along with the severity of their hearing loss, will have an important impact on these people as they move through the life cycle. Hammer (1980) reviewed current use of diagnostic and evaluation services for the deaf-blind. He followed three categories--medical, educational, and psycho-social--and compared them at four levels of development: infant/toddler; preschool; elementary school age; and adolescent/adult.

Review of this one paper revealed over 16 issues needing study. These issues are included in the following list.

ISSUES FOR STUDY

1. What percent of blind or visually impaired children have chronic otitis media? Does this affect learning? Does it affect social and psychological growth? (Hammer, 1980)

2. What factors provide for learning of socialization and how does the deaf-blind child move into becoming a part of society? (Hammer, 1980)

3. What does memory, organizational ability and context have to do with this attainment? (Hammer, 1980)

4. What effects do late onset health problems associated with CRS have on the behaviors of children and young adults? (Hammer, 1980; Shaver & Hicks, 1984)

5. Why are many of the deaf-blind adolescents regressing in their behavior and learning skills? (Hammer, 1980)

6. Why are many families of deaf-blind adolescents seeking other carekeepers for their adolescent son/daughter, such as: institutionalization or foster care facilities? (Hammer, 1980)

7. Have those diagnostic and assessment instruments used with deaf-blind children been good predictors of success/failure by adolescents/adults who are deaf-blind? (Hammer, 1980)

8. What studies have been done on effects of the auditory functions of the rubella deaf-blind adolescent? (Indication that hearing may become less functional in the congenitally rubella syndrome adolescents.) (Hammer, 1980; Brown & Karchmar, 1984)

9. Have researchers established/studied the patterns for sexual function and other related pattern of growth and programmed for them? (Hammer, 1980)

10. What studies have been done on the increased activity of seizures during adolescent years when at younger ages, they were controlled with medication? (Hammer, 1980; Shaver & Hicks, 1984; Brown & Karchmer, 1984)

11. Geriatric years often find new cases of deaf-blindness--what is being done to rehabilitate these elderly persons--who is monitoring and sharing the information?

12. Is the central nervous system of the rubella deaf-blind child mature enough by adolescence to stop sensory-motor learning or does the sensory-motor learning need to continue until a deaf-blind individual is well in his/her twenties? (Hammer, 1980)

13. What does a progressive loss, when it is diagnosed during adolescence, do to the psychological and social development of a deaf-blind adolescent? (Shaver & Hicks, 1984; Brown & Karchmer, 1984; Hammer, 1984)

14. Who is researching the outcome of parent involvement in program planning?

15. Has the movement from use of standard measures to "described attainment" helped deaf-blind persons? (Hammer, 1980)

16. How do the service providers' attitudes effect the behavior of the individual?

17. Have the methods for intervention of behaviors worked with this population?

18. Are techniques used for training professionals preparing them to deal with "burn out"?

19. What psychological effects does isolation have on the deaf-blind person?

20. Are methods of communication adequate to prevent withdrawal and isolation?

21. During the past few years, has the attitude of the general population improved toward deaf-blind individuals?

22. How closely related are growth and behavior of the deaf-blind adolescent?

23. How can we stimulate more data-based research in the area of deaf-blindness?

24. Is there one location for all the information generated by the Center for Services to Deaf-Blind?

Research in the above areas could provide a proven mechanism for assisting the CRS individuals in their effort to move into adulthood, and individuals with dual progressive losses in sight and vision to maintain their style of living. Research efforts in analyzing the vast amount of knowledge in the area of deaf-blindness could prepare society in readiness for another population "at risk".

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APPENDIX A

DEAFNESS ASSOCIATED WITH EYE DISEASES
Genetic Linked Syndromes

Syndrome	Hearing Loss		Vision Loss	
	Progressive	Non Progressive	Progressive	Non Progressive
1. Usher's Syndrome	X		X	
2. Alstrom Syndrome	X		X	
3. Retinitis Pigmentosa Nystagmus Hemiplegic Migrane, and Sensorineural Deafness	X		X	
4. Retinitis Pigmentosa Progressive Quadriparesis, Mental Retardation, and Sensorineural deafness	X		X	
5. Cockayne Syndrome	X		X	
6. Refsum Syndrome	X		X	
7. Inverse Retinitis Pigmentosa, Hypogonadism, and Sensorineural Deafness	X		X	
8. Retinal Changes, Muscular Wasting, Mental Retardation, and Deafness	X		X	
9. Cryptophthalmia Syndrome and mixed Deafness		X		X
10. Marshall Syndrome	X		X	

APPENDIX A - Cont'd.

Genetic Linked Syndromes -Continued

Syndrome	Hearing Loss		Vision Loss	
	Progressive	Non Progressive	Progressive	Non Progressive
11. Myopia, Blue Sclerae, Marfanoid Habitus, and Sensorineural Deafness	X		X	
12. Myopia, Peripheral Neuropahty, Skeletal Abnormalities, and Sensorineural Deafness	X		X	
13. Myopia and Congenital sensorineural hearing loss	X		X	
14. Myopia, Secondary Telecanthus (Hypertelorism), & Congenital Sensorineural Deafness		X	X	
15. Rosenberg-Chutorian Syndrome	X		X	
16. Optic Atrophy, Juveile Diabetes, & Sensorineural Hearing Loss	X		X	
17. Progressive Optic Atrophy & Congenital Sensorineural Deafness		X	X	
18. Optic Atrophy, Ataxia, & Progressive Sensorineural Hearing Loss	X		X	
19. Opticocochleodentate Degeneration	X		X	

APPENDIX A - Cont'd.

Genetic Linked Syndromes -Continued

Syndrome	Hearing Loss		Vision Loss	
	Progressive	Non Progressive	Progressive	Non Progressive
20. Iris Dysplasia, Ocular Hypertelorism, Psychomotor Retardation, & Sensorineural Deafness		X	X	
21. Harboyan Syndrome	X		X	
22. Familial Corneal Degeneration, Abnormal Calcium Metabolism & Deafness	X		X	
23. Norrie Syndrome		X	X	
24. Keratoconus, Blue Sclerae, Loose Ligaments & Conduct Deafness	X		X	
25. Progressive External Opthalmoplegia, Retina Pigmentary Degeneration, Cardiac Conduction Defects & Mixed Hearing Loss	X		X	
26. Tay-Sacks Disease		X		X
27. Leber's Congenital Amaurosis		X	X	
28. Hurler's Syndrome	X		X	
29. Albinism		X		X
Subtotal	20	9	25	4

APPENDIX A - Cont'd.

Prenatal Non-Genetic Linked				
30. Congenital Toxoplasmosis	X		X	
31. Congenital Cytomegalovirus		X		X
32. Congenital Syphilis	X		X	
33. Maternal Rubella	X		X	
Subtotal	3	1	3	1
Post Natal Non-Genetic Linked				
34. Retrolental Fibroplasia		X	X	
35. Neoplasma	X		X	
36. Trauma		X		X
37. Infectious Meningitis	X		X	
Subtotal	2	2	3	1
TOTAL	25	12	31	6

Categories:	Causes
Progressive Hearing Loss-Progressive Vision Loss	25
Progressive Hearing Loss-Non Progressive Vision Loss	0
Non Progressive Hearing Loss-Progressive Vision Loss	6
Non Progressive Hearing Loss-Non Progressive Vision Loss	6

APPENDIX B

CATEGORIES OF HEARING-VISION LOSSES RELATED TO CAUSE

1. Non-Progressive Hearing - Vision Loss

A.	Genetic Linked Syndromes	2	
B.	Pre Natal Non-Genetic Related	3	
C.	Post Natal Non-Genetic Related	1	
	TOTAL	6	17%

II. Non-Progressive Hearing Loss - Progressive Vision Loss

A.	Genetic Linked Syndrome	5	
B.	Pre Natal Non-Genetic Related	0	
C.	Post Natal Non-Genetic Related	1	
	TOTAL	6	17%

III. Progressive Hearing Loss - Non-Progressive Vision Loss

A.	Genetic Linked Syndrome	0	
B.	Pre Natal Non-Genetic Linked	0	
C.	Post Natal Non-Genetic Related	0	
	TOTAL	0	0%

IV. Progesssive Hearing Loss - Progressive Vision Loss

A.	Genetic Linked Syndrome	20	
B.	Pre Natal Non-Genetic Linked	3	
C.	Post Natal Non-Genetic Linked	2	
	TOTAL	25	69%

CHAPTER 4

PSYCHOLOGICAL, DEVELOPMENTAL AND MENTAL HEALTH RESEARCH PRIORITIES

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This very broad core area was intended to develop research questions, from psychological and psychiatric points of view, which would better elucidate the lives and the social/emotional needs of deaf-blind individuals. Group members were asked to address two major areas of investigation. Firstly, they were asked to formulate "researchable" questions aimed at a better understanding of basic developmental characteristics of the deaf-blind population. Secondly, group members were asked to detail research priorities which might help to define better typical "problems" presented by deaf-blind individuals seen for psychological treatment, to document clinical services and treatments appropriate for these individuals, and to formulate ways in which mental health treatment might become more accessible to deaf-blind individuals.

Comments from service providers, educators, rehabilitation workers and other researchers were solicited by questionnaire survey prior to the conference. Respondents provided more than 100 specific recommendations from which six broad areas of focus for psychological/psychiatric research about deaf-blindness emerged:

1) description of the psychological concomitants of hearing and vision impairment at any age;

2) "typical" and "atypical" patterns of cognitive, social, personality and communication development;

3) dynamics of stress, change and adaptation in the family of which a deaf-blind individual is a member;

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4) the impact of various intervention modalities now common in educational programming (and particularly the development of an "interactive" language system) on the social-relational capacity, self-concept and independent functioning od the deaf individual;

5) description of the "clinical" characteristics of individuals who are both vision-and hearing-impaired, which might have bearing on treatment modality in the mental health clinic;

6) development and/or adaptation of assessment techniques commonly used by mental health professionals.

These broad areas, suggested by professionals who have daily contact with deaf-blind individuals across the country, played a central role in the development of this group's priority concerns for research.

While the group took seriously its task to develop "researchable" questions, several philosophical stances taken about the conduct of research and the basic assumptions of investigators were taken before the group approached questions specific to the deaf-blind population. Probably the most important philosophical statement agreed upon by the group was that individuals classified (for educational, rehabilitation, medical or social service purposes) as deaf-blind make up perhaps the most heterogeneous group possible. Therefore, investigators approaching the study of "deaf-blindness" must present their findings in the context of detailed description of the particular individuals comprising their sample, and make no sweeping generalizations about the larger population of persons with both vision and hearing impairment. Linked to this first statement was the unanimous view that as researchers, academics, service providers, etc., we do not, at the present time, know enough about the developmental characteristics or the developmental potentialities of deaf-blind individuals. Research that will have meaning to the field in the coming years will be more descriptive and less quantitative, yielding a richer sense of the individual differences characterizing the deaf-blind population. Thirdly, investigators need to question assumptions regarding the high value of "normalcy" placed on deaf-blind individiuals by the society in which they live. For example, while it is without question, "normal" to develop language through vocal imitation of sounds heard, the implementation of a "treatment" or "intervention" for deaf-blind individuals based on this assumption of normal development, may not only be ineffective but also tremendously limiting and potentially damaging to the deaf-blind individual. Similar analogies could be drawn from other areas of "normal" development. Finally, the group felt very strongly that research investigating the mental/emotional/developmental status of deaf-blind individuals should attempt to frame questions from a viewpoint stressing potentials and capabilities, rather than limitations and incapacities.

From the six research areas defined by the field comment, the group defined three, more global, categories for investigators to address:

I. Living with Deaf-Blindness: The Experience of Deaf-Blind Individuals and Their Families
   A. Developmental patterns through the lifespan
   B. Families and other networks of support
   C. The existential experience of living with vision and hearing impairment

II. Language and Expression: The Key to Mental Health
   A. Modality influences on tactile linguistic codes
   B. Sociolinguistic phenomena

III. Clinical Services and the "Helping" Professionals
   A. Issues in the assessment of deaf-blind individuals
   B. The provision of mental health treatment
   C. Interpreter/guide/companion: The role of the interpreter with deaf-blind individuals

No order or priority was assigned either to the global categories or to the specific research questions defined within these. Rather, it was agreed that the present scarcity of research data documenting the development and socio-economic characteristics of individuals comprising the deaf-blind population mandated that any careful research in this area was, indeed, high priority reserach.

LIVING WITH DEAF-BLINDNESS: THE EXPERIENCE OF DEAF-BLIND INDIVIDUALS AND THEIR FAMILIES

Developmental Patterns Through the Lifespan. Clearly, research is needed about the development of persons who are deaf-blind from birth as compared to those who acquire this dual sensory impairment later in life. However, the diversity of the deaf-blind population, in terms of age of onset, severity of sensory limitation, and presence or absence of other handicapping conditions poses a great dilemma in establishing "normative" developmental expectations; these variables must be weighted heavily in determining what are "typical" vs. "atypical" courses of development.

Several recent reports (Wolf, Delk & Schein, 1982; RSA Prime Study Report, 1985) have attempted to delineate "subgroups" of the deaf-blind population so as to characterize accurately the differences and similarities observed when comparing individuals with both vision and hearing impairment. Typically these subgroupings have been made on the basis of several variables, particularly age of onset and/or severity of vision and hearing impairment. Both are important descriptor variables, since both may correlate significantly with level of independent

functioning, communication modality, capacity for communication exchange, and potential for optimal life "adjustment". However, because little is known about similarities or differences among individuals experiencing similar degrees of hearing and vision loss, or experiencing the loss of one or both sensory modalities at the same time of life, this is an important area for future research.

Several research questions can be defined which would provide better descriptive information about the developmental characteristics of deaf-blind individuals and would, at the same time, recognize the important differences resulting from the type of loss and the age at which the loss occurred. Intuitively, there appear to be at least four "subgroups" of individuals characterized by both vision and hearing impairment: congentially deaf-blind; congenitally deaf or blind; adventitiously deaf-blind; adventitously deaf-blind associated with old age. Individuals in these groups probably differ on many important dimensions. Developmental research must begin to describe the important within group and between group similarities and differences.

At present, only tentative information exists about:

1) characteristics shared by individuals losing hearing and vision early in life (congenitally, or within the first two years of life);

2) characteristics shared by individuals losing a second sensory modality (congenitally deaf or blind, and adventitously deaf-blind);

3) characteristics shared and differences observed between deaf-blind individuals who were congenitally deaf as compared to those congenitally blind;

4) characteristics shared by individuals experiencing the adventitous loss of both vision and hearing;

5) within-and between-group similarities and differences shared by those with similar degrees of vision and hearing loss.

An adequate description of the "subgroups" of the deaf-blind population must include at least these important "demographic" characteristics: age of identification; etiology of hearing and vision impairment; degree of hearing and vision impairment; presence or absence of other medical or physical limitations; ability for independent mobility; quality of orientation and mobility; modality and quality of communication; nature and extent of family and family support; nature and amount of "educational" intervention following diagnosis; capacity for independent functioning; etc.

From a developmental/psychological/mental health point of view, a full description must include several additional "outcome" measures: self concept; personal "experience" of being deaf-blind; "adaptive" functioning; quality of interpersonal relationships; network of support within the family and the community; life "fulfillment"; etc.

Additionally, a full description of "outcome" will incorporate the experiences and viewpoints of others who have significant roles in the deaf-blind individual's life. (i.e., What is the mother's, the father's the sibling's perspective about raising a deaf-blind child within the family setting? What is it like to have a parent who is losing both hearing and vision as a result of aging?).

FAMILIES AND OTHER NETWORKS OF SUPPORT

Research has shown that the birth of an impaired child is a traumatic event that emotionally alters the parents' birth experience and may greatly affect the developmental paths for mother, father, child and other family members (Stahlecker & Cohen, 1985; Beckman-Bell, 1980). In the case of those diagnosed with both hearing and vision impairment, this "diagnostic crisis" may occur at birth, but more often occurs at some later time in life. Regardless of the phase of life at which the diagnosis of dual sensory impairment occurs, it is to be expectable that significant emotional crisis will occur--for the individual and for those on whom that individual relies for support. Many important research questions can be defined for the deaf-blind individual and his/her family, specific to this period of "diagnostic crisis":

1) What are the ways in which family members (nuclear and extended) cope with the diagnosis and its implications?

2) What are the critical variables distinguishing families which adapt well to a diagnosis of deaf-blindness from those which adapt poorly?

3) What are the effects on family stability and roles (with the diagnosis of deaf-blindness for a family member), including quality of parental marriage, sibling social relationships, and additional demands made on siblings for care of the deaf-blind brother, sister or parent?

4) What are the effects on the family unit when a decision is made to place the deaf-blind individual out-of-home (ie. in a residential school, institution, foster home, group home, convalescent hospital, etc.)?

Identification of those variables which assist the deaf-blind individuals and his/her family in adaptive integration of the deaf-blindness will give direction to mental health clinicians and others in therapeutic efforts. Similarly identification of coping mechanisms which facilitate increased quality of life for a deaf-blind individual and his/her family certainly provides direction for more efficient and helpful intervention.

The concern with family structures must be generalized outside of the immediate family when one is dealing with some deaf-blind populations. Specifically, it would appear that residential school or treatment settings often seem to perform some of the functions of the family (i.e., provision of affection and emotional support, transmission of cultural values, etc.), and that individuals involved in these extrafamilial institutions (i.e., service providers, teachers, peers) may fill roles analogous to those of the more traditional nuclear family. If this notion has some validity, then identification of the variables within those family and family-like structures which correlate with facilitative and detrimental impact on the deaf-blind individual will be helpful in guiding the efforts of both clinicans and program planners.

Given that the "diagnostic crisis" will have significant impact on the individual and his/her family/family-like unit, it is also important to understand what impact dysfunction in the family or family-like unit (e.g., substance abuse, major depression, psychosis, sexual dysfunction, etc.) will have on the development of the deaf-blind individual. It is possible that the sensory impairments of the deaf-blind member may, at times, "protect" him/her from the dysfunctionality of the family, since he/she is often restricted from the full range of information available within the family unit. To gain an understanding of the dynamic of the family situation several additional questions must be addressed.

1) How do family members communicate (both formal communication and the transmission of "warmth" and "caring") with the deaf-blind individual?

2) For adult deaf-blind individuals, who provides social support and the role functions of the family?

3) What "adaptations of role" occur in the family in which a parent becomes both hearing and vision impaired?

Finally, parents and teachers (or other service providers) may make observations which cannot be corroborated (or at least interpreted in the same way) by mental health professionals. This may occur because of the setting in which observations are made by the mental health professional or because the specific behavior patterns in question are not displayed in the short time available for an "assessment". It may also occur because the parent and the professional do not make similar attributions on

behaviors the child is observed to make. For example, a parent may view a behavior such as appropriate use of table utensils as a sign of normal intelligence, while a service provider dismisses the behavior as having no relevance to intellectual functioning. The difference in interpretation or attribution may have a major effect on the judgement of intelligence or potential for further development, and on the family's functioning vis-a-vis the "helping" professional.

1) What effects does family/professional dissonance have on family members, and what can be done to minimize this "credibility gap"?

2) What are the effects of validation by service providers of family member attributions on variables such as seeking program access, program compliance, family stress, degree of confidence in service providers, etc.?

THE EXISTENTIAL EXPERIENCE OF THOSE LIVING WITH VISION AND HEARING IMPAIRMENT

When clinical issues and treatment modalities related to deaf-blind clients are discussed, one vital area of information is missing. We know very little of the subjective experiences of deaf-blind people. While communication issues may hinder both clients' abilities to express this information and researchers' abilities to receive it, information must, nonetheless, be made available. Not to have reliable data on aspects of deaf-blind clients' existential experience is to invite misunderstanding, misdiagnosis and mistreatment as a result of unquestioned assumptions and beliefs from the professional community.

Little, if any, research has focused on the intrapersonal experiences of deaf-blind people.

1) What does the world feel like, sound like and look like to one with auditory and visual limitations?

2) How do deaf-blind individuals experience themselves in terms of sexuality, self-concept, self-worth and self-esteem?

3) What is the subjective experience of "thinking" or "feeling" to the deaf-blind individual?

4) Does the deaf-blind individual have perceptions about the hearing and sighted world, and if so, how do these perceptions correlate with the degree of loss, etiology of loss, quality of social relationships, communication mode, etc.?

LANGUAGE AND EXPRESSION: THE KEY TO MENTAL HEALTH

It is through language that humans share experience, including the internal experience represented by thoughts and feelings, and indeed through which humans structure their experience. Language allows the past to be brought into the present and the present to be projected into the future. It is probably the major human characteristic, the prime defining feature of "personhood." It is a truism, then, that the sort of efficient communication and infinite range of possible meanings capable of being encoded by natural language are crucial to education, rehabilitation, and the mental well being of humankind. Without it, enormous and perhaps insurmountable obstacles are placed in the way of those who would take on the task of providing any significant human services.

The auditory sense is apparently the most "natural" channel for linguistic encoding. In all cultures, in all individuals without sensory or other interfering impairments, language is overwhelmingly an oral/aural phenomenon, with gestural phenomena playing a very minor secondary role, tactile phenomena a minuscule tertiary role, and the gustatory senses no remarkable role at all. In fact, until recently the auditory sense was taken to be the sine qua non of natural language. Increased investigation of the gestural phenomena displayed by communities of deaf individuals has called into question the necessary primacy of audition for language, and most sophisticated linguists currently would agree that while the oral/aural channels clearly have some special status in natural language, they are by no means crucial to linguistic functioning. It seems that natural language and human linguistic functioning is independent of modality--a higher cognitive function that for various reasons is most efficiently manifested auditorily, but is not restricted to such manifestations.

An individual whose linguistic functioning is bounded by the severe auditory and visual deficits of deaf-blindness is clearly at some sort of disadvantage, if for no other reason than the fact that those in society who have the role of transmitting linguistic knowledge (i.e., parents, peers, members of the larger community) most often don't share the deaf-blind individual's sensory limitations. It is the premise of this portion of the report, however, that the disadvantage is not crucially limiting. There exists a modality through which linguistic functions of deaf-blind individuals can be and most frequently are manifested, namely the tactile senses. There is a corollary premise that until significant evidence to the contrary is presented, tactile senses must be taken to be the most appropriate and efficient channels for language and communication functioning in deaf-blind individuals.

It is recognized that making assumptions such as those stated above can be potentially dangerous. Such assumptions may be misconstrued as applying to deaf-blind individuals regardless of the severity of their sensory limitation(s), and disregarding their potential for utilization of

"residual" auditory and visual input for communicative exchange. It is important, however, that research address questions related to the use of the tactile modality for communicative exchange, and that current knowledge on tactual sensation be integrated with the field of linguistics and lead to the formulation of a "linguistics of tactual language." This call for research is divided into two broad topic areas. The first area concerns modality influences on linguistic phenomena. More specifically, the questions under this area concern the boundaries on linguistic encoding inherent in a tactile linguistic code. The second area concerns sociolinguistic phenomena. The questions under this area concern "tactile linguistic communities" (i.e., phenomena seen in continuing groups of deaf-blind individuals who use various tactile linguistic codes.)

MODALITY INFLUENCES ON TACTILE LINGUISTIC CODES

It is fairly clear that language as a cognitive process has at least some level of organization independent of modality. For example, the various representations of language (i.e., phonetic or syllabic, pictorial, ideographic, etc.), even if derivatives of the auditory code, are not the same as the auditory code and can be interfered with independently. That is, there are conditions which leave auditory language production and comprehension intact while impairing formerly intact reading and writing skills. There is evidence that linguistic encoding and decoding functions are organized differently, depending on writing systems used by the particular individual. Specifically, brain dysfunction in the right hemisphere appears selectively to impair production and comprehension of pictorial and ideographic linguistic codes while leaving phonetic and syllabic encoding and decoding intact.

There is also fairly clear evidence that linguistic modality influences the formal properties of the linguistic code. For example, spoken language must to a large degree be linear and digital: morphemes (or the meaningful units of language) are produced one after the other in a string by speakers. When the modality shifts from auditory to visual-spatial (as it does in American Sign Language), other possibilities present themselves and are in fact utilized. Meaningful units of sign language occur simultaneously, the grammar of the language takes on several analog characteristics, and there is a productive use of certain types of iconicity (DeMatteo 1976).

With respect to the assumption made above, namely, that tactile senses present the most effective modality for the linguistic functioning of deaf-blind individuals, several questions relevant to the modality present themselves. Tactile sensation is highly specific while auditory and visual sensation operates in a much more general fashion. That is, an auditory stimulus generally is received by both ears and a visual stimulus by both eyes. The whole sensory system is stimulated. If one of the end organs in either the visual or auditory modality is impaired, the

unimpaired organ receives the stimuli and transmits information to both halves of the brain. Tactile stimulation, on the other hand, is generally received only by a limited number of sensory receptors. If tactile receptors are impaired, intact receptors cannot "take up the slack," and no information gets to the brain. In this way, tactile linguistic codes would appear to be much more subject to intrusion by limited sensory deficits than would auditory or visual linguistic codes. What then, are, the linguistic implications of specific tactual deficits on tactile linguistic functioning? Several questions can be formulated:

1) Do deaf-blind, tactually communicating individuals who display peripheral tactile deficits or more cortically organized tactile suppressions (i.e., in which bilateral simultaneous stimulation is perceived as unilateral single stimulation) show linguistic deficits as well?

2) Are such deficits limited to perception alone, or are higher linguistic processes affected?

3) What are the encoding possibilities of the various parameters of tactile sensations (pressure, kinesthetic or proprioceptive mechanisms, rhythm, etc.)?

4) Do certain parameters lend themselves to more efficient processing of particular types of linguistic material than do others?
   (a) What is the brain organization of linguistic functions in individuals whose first and primary language has been in the tactile modality?
   (b) Does the brain organization of linguistic functions in individuals whose first and primary language has been in a non-tactile modality influence linguistic functions when modality must be shifted to tactual mechanisms (i.e., when an individual is becoming visually and auditorily impaired)?
   (c) What does our knowledge of the tactile senses tell us about linguistic functions (and possible linguistic functions) when one's language functioning is dependent on tactile sensation?

Another class of questions relative to modality influences concerns non-linguistic communication (e.g., "body language"). Although affective information, emphasis, truth value, and other meaningful features of communication have formal linguistic manifestations, they are also communicated in non-linguistic or meta-linguistic ways by tone of voice, body posture, facial gesture, and so forth.

1) How is such information conveyed in tactual communication systems? Indeed, is it conveyed at all non-linguistically?

2) How do combined visual and auditory deficits affect overall (i.e., not merely linguistic) communication functions?

SOCIOLINGUISTIC PHENOMENA

It is a truism that humankind are social creatures and that ongoing social interaction facilitates general mental health. Indeed, social withdrawal is strongly associated with serious psychopathology such as major depression, schizophrenia, and character pathologies. It is also true that the rubric "social community" is in many ways interchangeable with "linguistic community," and that to understand the former in any comprehensive fashion, one must have sufficient understanding of the latter. In short, an adequate understanding of the components of mental health in deaf-blind populations requires knowledge of how deaf-blind individuals function in groups, both socially and linguistically.

Initial efforts toward understanding adaptive functioning in groups of deaf-blind individuals might be directed toward gathering descriptive data on existing communities of deaf-blind persons. There are apparently a number of substantial communities of deaf-blind persons in various areas of the country, and gatherings such as those of the American Association of the Deaf-Blind continue to facilitate the building of "community" for deaf-blind individuals. Once identified, several important questions may be addressed about these communities of deaf-blind individuals.

1) What are adaptive and beneficial characteristics of communities of deaf-blind individuals?

2) What social norms govern behavior in these communities?

3) What is the general social structure of the communities?

4) What are the "methods" of these communities (i.e., community institutions, rituals, problem resolution methods, humor, social interaction patterns, values, expression of affections, etc.)?

5) How do deaf-blind persons find and enter such communities?

Although the answers to these more specific questions will likely involve sociolinguistic phenomena, there are other questions which deal more directly with sociolinguistic functions. Here, the general arena of concern is the development and evolution of linguistic functioning in communities of deaf-blind persons. The specific questions are these:

1) How do deaf-blind persons most efficiently communicate among themselves, particularly those who, within the community, are judged to be good communicators? By looking at linguistic communication within deaf-blind communities descriptively, one then can make some prescriptive statements to those whose task it is to assist in other deaf-blind persons' language development.

2) Are there code switching phenomena within deaf-blind linguistic communities and correlated social stratification phenomena? Code switching, or the alternation between forms of linguistic expression depending on social context, plays an important social role in many oral linguistic communities and clearly plays an important role in the ASL linguistic community. The deaf signer who is able to switch between rapid and fluent ASL and, for example, manually coded English, depending upon the addressee of the communication, has much greater social status than the signer who is fluent only in ASL.

3) What is the social impact of the use of what obvious devices (i.e., does it label the user as deficient, less intelligent, lazy, or in other pejorative ways)?

4) What are the most effective ways of teaching educators, rehabilitation workers, counselors, and other service providers for the deaf-blind community to be good tactile communicators?

CLINICAL SERVICES AND THE "HELPING" PROFESSIONALS

Surely the various deaf-blind populations have at least those mental health needs that the hearing and sighted population has. It is likely that their needs are even greater. Yet, in a recent report on the service needs of deaf-blind persons in Canada (Committee on Services to Deaf-Blind Persons in Canada, 1984), direct mental health service needs were not even addressed. In a similar report in this country outlining a model service delivery system for deaf-blind persons (Watson, Barrett & Brown, 1984), mental health needs were addressed only at the level of peer group, vocational, personal, and family counseling. Family counseling was seen as appropriately focused on adjustment to the disability, no mention being made of other mental health needs a family might have.

It is probably the case that the extensive needs of deaf-blind persons in so many areas of functioning overwhelm attention to mental health needs (which, presumably, would be of concern for only a minority of the deaf-blind population). At the same time, there are no good data on what the mental health service needs of deaf-blind persons are, and it would seem inappropriate to concentrate on other needs to the exclusion of mental health services without first formulating some reasonable hypotheses about and reliable information on what those needs might be.

ISSUES IN THE ASSESSMENT OF DEAF-BLIND INDIVIDUALS

General psychological assessment. In developing individual intervention programs to meet education, vocational rehabilitation, and mental health needs, it is usually helpful to have some assessment of general intellectual potential and/or general personality characteristics. IQ scores have diagnostic implications and affect

treatment access in many cases; descriptions of functional abilities can focus and direct remediation efforts; and personality variables may determine appropriate treatment efforts. Such assessment may also be used in an ongoing fashion to track progress in education, rehabilitation, and treatment. While it is true that assessment has a potential for misuse in the labeling and categorizing of individuals without meeting indicated needs, such potential argues against inappropriate use of assessment rather than against assessment per se.

There is no well established set of standards against which a deaf-blind individual's functional abilities can be measured. Which functional differences represent expected "deviations from the norm" given the population and which represent true deficits even in a sensorily impaired population? With respect to the various populations of deaf-blind individuals, instruments, techniques, and standards need to be developed which will allow appropriate assessment of current intellectual functioning, intellectual potential, social skill development, behavioral characteristics, problem solving style and ability, and other adaptive behaviors. At present, it is not possible to provide reliable and reasonably accurate assessment for deaf-blind individuals, especially those who have congenital or prelinguistic onset of sensory impairments. As a result, many of these individuals receive inappropriate assessment or no assessment at all.

Diagnosis of major psychiatric disorders. Individuals with severe auditory and visual deficits are as likely to suffer major psychiatric disturbances as non-sensorily impaired individuals. It is not clear, however, that the behavioral manifestations of such disturbances are isomorphic or even similar to those one would expect in the sensorily intact. For example, Evans and Elliott (1981) found that the behavioral manifestations of schizophrenia in deaf patients were in many cases distinct from those in hearing patients. They also found that some of the behaviors indicative of schizophrenic disorders in hearing individuals were not diagnostic in deaf patients. It is reasonable to suspect, then, that a descriptive nosology of psychiatric disorders appropriate for a deaf-blind population will use behavioral descriptors different from those for a sensorily intact or even a deaf population.

Current standard practice in psychiatry and psychology calls for fairly strict behavioral criteria for the diagnosis of psychiatric disorders. The current Diagnostic and Statistical Manual of Mental Disorders, or DSM-III (American Psychiatric Association, 1980) uses constellations of typical behaviors seen in particular disorders and allows diagnosis of a disorder in cases where an individual exhibits a specified number of those behaviors. If such diagnostic behaviors are different for a deaf-blind population, then it is necessary to formulate appropriate behavioral constellations for diagnostic use in that population.

Neuropsychological assessment. Brain dysfunction is typically associated with behavioral disturbance. Neuropsychological evaluation involves formal assessment of behavioral expressions and manifestations of impaired brain functioning and involves the systematic examination of cognitive functions, of sensory-perceptual and motoric abilities, and of the emotional and motivational aspects of personality. Neuropsychological examination of these areas of functioning is ordinarily accomplished by utilizing standardized tests, clinical procedures, and observational data that have been demonstrated as clinically useful and psychometrically valid in discriminating individuals with impaired brain function from those without such impairment.

In clinical and rehabilitation settings, neuropsychological evaluations are most often performed to aid in determining if an individual has an organic brain disorder that might be responsible for disturbances in behavior and functioning and/or to facilitate the planning and implementation of appropriate treatment, rehabilitation, disposition, and management efforts with a particular client (Lezak, 1983). In addition, neuropsychological evaluation can be useful in assessing the effectiveness of specific interventions with a client, in evaluating the effectiveness of a treatment or rehabilitation program, in monitoring the course of a neurological illness, in providing information relevant to legal/forensic decision-making, and in the research investigation of brain-behavior relationships (Strub & Black, 1981).

In performing a neuropsychological examination, the neuropsychologist makes use of multiple sources of information regarding the client's cognitive, perceptual-motor, and emotional-motivational behavior, interpreting the results by using a variety of inferential methods to draw conclusions about the probability of a brain disorder being present. Typically, inferences are based upon: (a) the level of a client's performance on quantified tests and measures as compared to normative data for expected performance; (b) the presence of specific pathognomonic signs of brain disorder; (c) the presence of identifiable constellations of spared and impaired abilities, of efficient and deficient performances, and of specific pathognomonic signs that are recognized as characteristic of specific neurologic and neuropsychiatric disorders; (d) comparison of the sensory-perceptual and motor functions of one side of the body with the same functions on the other side, one side of the body serving as a control or monitor against which to evaluate the performance of the other side of the body.

The neuropsychologist can draw conclusions regarding the probable presence or absence of a brain disorder, the location of the dysfunction, the probable onset of the disorder, the likely course of the disorder, the severity of the disorder and, in some cases the probable etiology or cause of the brain dysfunction.

Neuropsychological evaluation has a number of advantages not shared by most other standard neurodiagnostic techniques: (a) It is noninvasive and carries no risk of mortality or morbidity. (b) It can provide important descriptive and prognostic information that other diagnostic procedures cannot (Strub & Black, 1981). Despite the tremendous advances in medical diagnostic technology, there are many conditions in which scans and other laboratory data are not diagnostically helpful and in which neuropsychological findings can be crucial (Lezak, 1983). For example, neuropsychological assessment has proven especially useful in discriminating between psychiatric and neurological symptoms and in identifying brain dysfunction not associated with structural abnormality.

The deaf-blind population is no less vulnerable to the most common causes of brain dysfunction than is the hearing population. Head trauma, cerebral tumors, toxic disorders, and most other causes of brain pathology are as probable occurrences in sensorily impaired as in unimpaired persons. Moreover, when the impairment is caused by maternal rubella, Rh incompatibility, prematurity, anoxia, or meningitis, there is an increased risk of brain dysfunction (Isselbacher, Adams, Braunwald, Petersdorf, & Wilson, 1980; Vernon, 1968) as these conditions result in an assault on the fetus' or child's developing central nervous system (CNS).

It is extremely important for the human service professional to have an accurate evaluation of the client in order to provide relevant and appropriate services. The deaf-blind client who has poor language skills, difficulty maintaining attention, and who tends to behave aggressively at home or on the job site because of neurological dysfunction may present the same symptoms and problems as the emotionally disturbed deaf-blind individual who grew up in a family without communication, who is without sufficient socialization, and whose functional developmental deficits make it difficult for him or her to monitor feelings or develop good relationships. Although these two individuals may present a very similar picture in terms of their patterns of behavior, their service needs and potential for benefiting from services are quite different. Even in cases in which the undiagnosed and untreated brain disorder poses no threat to life, it can severely impair the individual's ability to function and can limit quality of and satisfaction with life. Referral for appropriate medical and psychiatric/psychological care, rehabilitation services, and educational and psychosocial interventions depends upon initial identification of those clients having brain disorders.

Specific assessment research needs. Unfortunately, there is little known about how one might go about accomplishing adequate psychological or neuropsychological assessment with individuals with the sort of sensory deficits seen in those individuals labeled "deaf-blind." Many of the techniques referred to above use vision and hearing and depend upon intact end-organs (i.e., ears and eyes). Moreover, the base of "shared experience" the psychometrist depends upon in using normative test values cannot be assumed when the subject has been sensorily deprived during development.

With respect to the various deaf-blind populations, a great deal of basic and applied research is needed in the area of psychological assessment in general, and in neuropsychological assessment in particular. Such research properly should have several foci:

1) The development of novel techniques for assessing various cognitive functions such as attention, memory, numerical reasoning, spatial reasoning, functioning of residual hearing and sight, orientation, abstraction ability, judgment, language functions (particularly in the individual's usual language mode), general problem solving ability, social behavior, motoric skills, etc.

2) The gathering of appropriate normative values for those psychometric instruments which are not interfered with by the sensory deficits.

3) The development of new assessment instruments where needed.

4) Basic research on patterns of behavior and test performance correlated with varieties of brain dysfunction.

5) Basic research on functional brain organization with congenital and prelinguistic onset deaf-blindness.

6) The development of diagnostic criteria for major psychiatric disturbance in the various deaf-blind populations.

THE PROVISION OF MENTAL HEALTH TREATMENT

Issues Related to Psychotherapeutic Intervention. When therapists evaluate most clients with respect to what sort of psychotherapy modality would be most appropriate, they may depend on a relatively consistent framework within which to perform that evaluation. In general, for example, a therapist can assume that he or she shares with the client a language, a set of cultural concepts or values (e.g., family, parents, sharing, affection, anger, etc.). In other words, therapists can generally assume that while each client is unique and individual in many ways, most clients share a similar background of knowledge, values, and "life experience". The unique qualities of the life experience of the deaf-blind individual are discussed elsewhere in this report. Suffice it to say here that the clinician who is given the task of providing services to a deaf-blind person, whether that service is psychotherapy, mental health counseling, diagnosis, or more in depth assessment, cannot generally depend on common knowledge, the shared expertise to be found in an extensive clinical literature, or even in many cases a large experiential base.

There are various types, modalities, and levels of psychotherapies. In modern psychiatry, psychology, counseling, and social work, one finds practitioners of many different therapies with names such as behavioral therapy, cognitive-behavioral therapy, psychodynamic therapy, systems therapy, body-oriented therapy, psychoanalytic therapy, and so forth. Beyond such a nomic taxonomy, there are several other dimensions along which therapies can be categorized. They may be brief or long-term; they may be supportive and defense building or more insight oriented and defense revealing; they may be oriented toward talking and thinking, or oriented toward behavior and action; they may take the individual as the unit of treatment or a larger network of which the individual is a part; they may be highly structured and concrete or ambiguous and abstract. In short, there are several decisions for the therapist to make in providing psychotherapeutic intervention with any client. The problem is much more complicated when the client to be served has the unique needs connected with severe sensory impairments.

There is very little known about the sort of mental health services needed in the various deaf-blind populations, how one might go about providing needed services (either at a programmatic level or on an individual basis), or about appropriate therapeutic techniques for these populations. These global questions ultimately reduce to more specific informational questions amenable to research investigation. Below are some questions whose answers are prerequisite to appropriate psychotherapeutic intervention.

Issues related to family intervention. Many service providers see family therapy as the treatment of choice for exploring issues relating to any disability in a family member. There is a controversy within the community of family therapists treating families with hearing impaired members, however, over the use of interpreter services. On one side of the issue are those who feel that the use of an interpreter serves to increase family communication, eases the therapeutic process both for family members and for service providers, provides appropriate access to information for the deaf member, and models appropriate use of interpreter services, among other effects. On the other side of the issue are those who feel that use of an interpreter creates an artificial environment which does not allow the service provider to work with the family as it generally functions, to intervene on natural communication patterns and mechanisms, or to confront any denial of communication difficulties between hearing and deaf family members. Obviously this controversy generalizes naturally to families with deaf-blind members.

1) How does use of an interpreter affect outcome or duration of family therapy where a deaf-blind individual is included?

Issues related to programmatic intervention. It is expected that a certain proportion of the various deaf-blind populations will at some time require programmatic mental health services (i.e., inpatient psychiatric

services, residential treatment, day treatment services, specialized programs such as substance abuse treatment, treatment for physical or sexual abuse, etc.).

1) What is a the most effective setting for programmatic treatment of deaf-blind individuals?

2) What are effective and efficient treatment modalities (i.e., milieu treatment, group treatments, behavioral interventions, highly structured programs, etc.)?

3) How can currently existing treatment settings and facilities be modified to be both accessible and therapeutic for deaf-blind individuals?

Other issues related to psychotherapy. Several other questions are of concern to service providers offering psychotherapeutic services to deaf-blind populations. Some of them relate to interpreter use and are addressed elsewhere. Others are the following:

1) What are appropriate training models for clinicians who plan to work with deaf-blind populations?

2) Can specific personality characteristics, behavioral tendencies, or coping mechanisms be predicted on the basis of etiology of the sensory impairments?

3) Are certain types of therapies (i.e., supportive vs. depth, insight vs. behavioral, etc.) more effective with certain deaf-blind populations without respect to characteristics of the individuals?

4) In addition to their effect on target symptomes, what is the impact of psychotropic medications on functioning (i.e., functioning of residual vision, motoric abilities, tactile functions, and other functions crucial to adaptive functioning in a sensorily impaired individual)?

INTERPRETER/GUIDE/COMPANION: THE ROLE OF THE INTERPRETER WITH DEAF-BLIND INDIVIDUALS

Deaf-blind people use interpreters/guides for most aspects of their education, rehabilitation, social contact and community life. The relationship between interpreters and deaf-blind individuals is significantly different from that of interpreters and deaf people in terms of: 1) actual time spent with the interpreter; 2) physical proximity while working; 3) role expectations placed upon the interpreter; and, 4) need for social (in addition to professional) time together while in a

"work" setting. Very few interpreters are adequately trained fully to meet the needs of deaf-blind individuals (as opposed to deaf-only individuals). Several important questions must be posed to gain a better understanding of the specific qualities, skills and attitudes needed by interpreters qualified to do such interpreting.

1) What are the major roles and functions performed by interpreters for deaf-blind individuals?

2) What are the skills necessary for each role?

3) What is the role of the interpreter in the deaf-blind community?

4) What (if any) is the collective preference of deaf-blind individuals for interpreters' language, skills style, personal qualities,
etc.? How do these preferences influence the interpreter/client relationship?

Interpreters for deaf-blind people are responsible for conveying much more information than simply what is "said" in a conversation, meeting, or speech. Interpreters for deaf-blind individuals must convey information regarding the environment (who is in the room, where they are situated, the apparance of the room and the social "tone" of the setting), and regarding the quality of interaction between individuals (both verbal and nonverbal). In addition, interpreters serve as guide for the deaf-blind individual, and often as social companion during "non-interpreting" periods of time. The nature of this relationship poses several important questions regarding the interpreter as a person and how the interpreter's own way of "viewing the world" influences the messages sent and received by the deaf-blind individual.

1) What are the implications of this type of intimate (proximal) contact, often for long hours, on the interpreter/client relationship?

2) What is the effect of the interpreter's personality, linguistic style, motivation and attitude toward the deaf-blind individual as information is "filtered" to that individual?

3) What kinds of information (e.g. environmental, linguistic, affective, "meta-message", etc.) are most commonly "lost in the translation" for the deaf-blind individual?

4) What is the effect on the deaf-blind individual's full understanding and participation, given such inevitable omissions in interpretation?

5) What are effective ways of interpreting the environment--human and non-human; dynamic and static?

6) In which situations can deaf interpreters be most effectively used and in which situations are hearing interpreters most effectively used?

Finally, because the relationship between interpreters and deaf-blind individuals is intimate and intense (in terms of contact and content) and often continues for years, important ethical and professional questions may be posed.

1) How do relationships that develop between deaf-blind individuals and their interpreters differ from those which develop between deaf individuals and their interpreters?

2) In what ways are these close relationships between interpreter and deaf-blind individual helpful to the deaf-blind individual? In what ways, if any, can they be potentially harmful?

3) What professional standards may be inappropriate or difficult to follow when interpreting for the deaf-blind client? Is there need to modify (or develop) standards for interpreting with deaf-blind clients?

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CHAPTER 5

RESEARCH ON EDUCATIONAL PRACTICES AND PROCEDURES EMPLOYED WITH CHILDREN AND YOUTH WHO ARE DEAF-BLIND: PAST, PRESENT, AND FUTURE PERSPECTIVES

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INTRODUCTION

There is a dearth of empirical research on the education and training of persons who are deaf-blind. Data derived from the study of other handicapped populations is frequently applied to the deaf-blind population, the assumption being that what is effective for individuals with "similiar" handicaps will also be effective for an individual who is deaf-blind.

The generalization of empirical findings from studies of the deaf, the blind, or the multihandicapped to persons who are deaf-blind is both the field's greatest asset and its greatest liability (Blea & Overbeck, 1977). On the one hand, the utilization of information from other areas of exceptionality has enabled the field of deaf-blind education to progress fairly rapidly, benefiting from the reported successes and mistakes of others. On the other hand, this reliance on research from different areas of special education has, resulted in a lack of initiative to investigate approaches specific to children and youth who are deaf-blind. Moreover, "there is little or no empirical validation that the techniques used successfully with other exceptionalities are also appropriate for use with a deaf-blind child".

The efficacy of educational methods and procedures currently employed with persons who are deaf-blind needs investigation. These include: (a) practices that are derived from other areas of exceptionality and subsequently, applied with students who are deaf-blind; and (b) practices that are specific to the deaf-blind population. An additional need exists to conduct scholarly research on innovative educational methods that have the potential to effect positive behavioral change in children and youth who are deaf-blind and, hence, to foster greater independence in both current and future environments.

Characteristics of Research in Deaf-Blind Education

Stainback and Stainback (1984) describe quantitative research as a method for identifying facts and causes of human behavior through the generation of objective, observable, and quantifiable data. Qualitative research seeks to identify and understand peoples' perceptions of behavior and events that take place in the environments where they naturally occur. Quantifiable data may be generated within "laboratory" settings or in specially structured classroom situations. Qualitative data is generated from observations of spontaneous behavior in the natural educational milieu (i.e., the educational classroom; the home environment; and/or community environments).

Most research on the education of deaf-blind persons has employed quantitative methods. Although the effectiveness of the investigated procedures is demonstrated in controlled situations, Stainback and Stainback (1984) warn that it cannot be inferred that these will have the same impact in natural environments. They feel that a "blending" of the assets of both quantitative and qualitative research is required, if efficacious educational practices are to be identified. Yoshida (1984) concurs: the "...first order of business is to describe and define salient variables concerning instructional programs and student progress...in real-life service delivery settings such as classrooms" (p. 26).

Among the many limitations of existing research in the field of deaf-blind education, Blea and Overbeck (1977, p. 254) list six factors that they feel are most contributory.

1. Few empirical studies are conducted with deaf-blind persons as the target population.

2. Few existing research reports provide objective guidance to educators (i.e., they are primarily case studies, narrative reports, or position papers).

3. Many reports are esoteric or molecular in focus, providing little assistance in the day-to-day delivery of services.

4. Potentially helpful reports have limited distribution (i.e., they may only be known to a few teachers or agencies).

5. Many articles provide "how-to" or "how-we-did-it" information with little data to substantiate the efficacy of the techniques.

6. Much of the research taking place in educational programs for deaf-blind children and youth is not reported.

This review of the literature will focus on the characteristics of children and youth who are deaf-blind, on the characteristics of educational programs and educational service delivery systems, on the comprehensive assessment of both students and educational programs, on the roles and requirements of teachers, and on critical variables in the preparation of personnel.

CHARACTERISTICS OF DEAF-BLIND STUDENTS

Children and youth who are deaf-blind constitute a heterogeneous group. A great variability exists in the type and intensity of the handicapping conditions they manifest, their needs for special services, and their ultimate learning potential (Cassell, 1984; Day, 1983; Myers, 1981; Robbins, 1977; Smithdas, 1980). Even when deaf-blind students are clustered in school programs, it is difficult to achieve a relatively homogeneous grouping (Heward & Orlansky, 1984; Spar, 1972).

The multisensory impairment of deafness and blindness is a compound, rather than an additive condition (Brannan, 1982; Kennedy, 1973). Hart (1977b) proposed that deafness and blindness are not separate handicaps when encountered in a singular individual, but intertwined in their impact on overall performance. Smithdas (1980) notes that blindness limits a person's contact with things, whereas deafness limits a person's contact with people. He says, "...deaf-blindness creates unique problems of communication, mobility, and orientation peculiarly its own" (p. 1015).

Most students who are deaf-blind have some residual vision and/or hearing (Day, 1983; Kates & Shein, 1980; McInnis & Treffry, 1982). More than 50% of the children and youth being educated as deaf-blind are "visual", i.e., partially sighted (Myers, 1981). Vision was considered to be an asset in 67% of the deaf-blind students studied by Curtis, Donlan and Tweedie (1975). A majority of deaf-blind students served by Franklin (1979) also had some residual hearing.

The age of onset of either deafness or blindness has varying effects on an individual's educational and counseling needs. Smithdas (1980) states that the personal adjustment of a person who is adventitiously deaf-blind is more traumatic than that of a person who is congentially deaf-blind. Kates and Shein (1980) note that blind people who are deafened tend to "resemble" persons who are blind, and deaf people who are blinded tend to "resemble" persons who are deaf. Day (1983) and Vernon (1977) concur that students with Usher's syndrome (i.e., persons who are congenitally deaf and later become blind) are typically served in programs for the hearing impaired.

Children and youth who are deaf-blind typically have multiple disabilities, in addition to visual and auditory impairments (Flathouse, 1982; Jensema, 1974; Lowell, 1977; Robbins, 1977; Vernon, 1982; Vernon & Hicks, 1980). Sixty-seven percent of the deaf-blind students Jensema (1979) studied had disabilities other than sensory impairments. Additional handicapping conditions may include cerebral palsy, autism, mental retardation, health impairments, central nervous system defects, behavioral disorders, aphasia, and learning disorders (Bettica, 1979; Day, 1983; Vernon, Grieve, & Shaver, 1980). These concomitant handicapping conditions may result in defects in comunication, cognition, motor skills, independent mobility, physical orientation, adaptive behavior, and general development (Heward & Orlansky, 1984; Spar, 1972; Stein, Palmer, & Weinberg, 1982). Deaf-blind students may also have eccentric developmental patterns within and across areas of educatinal concern (Mira & Hoffman, 1974).

The intellectual capacities of deaf-blind students range from average intelligence, to mental retardation, to giftedness (Spar, 1972). Day (1983) feels that the majority of deaf-blind students are at least functionally retarded. Seventy-five percent of the students studied by Jensema (1979) in 195 classrooms for the deaf-blind were mentally retarded, with 60% having severe to profound mental retardation. Stein, et al., (1982) estimated that 79% of their deaf-blind subjects fell into the "middle trainable and below" range, with only 17% in the "upper trainable" or "low educable" range.

Intellecutally gifted deaf-blind students must be provided for also (Spar, 1972). Although the contributions of exceptional deaf-blind individuals, such as Robert Smithdas and Helen Keller, are well known, Day (1983) and Myers (1981) state that probably no more than 50 gifted deaf-blind people have been identified world-wide since the beginning of this century. The mother of a deaf-blind adolescent comments that she "...doesn't believe one is likely to find many Helen Kellers within the population of deaf-blind children" (Smith, 1984, p. 3).

Issues in the Definition of Deaf-Blind Students

The diverse characteristics and educational needs of children and youth who are classified as deaf-blind cause contention among educators. Three schools of thought exist as to which students should be served in specially designated classrooms for the deaf-blind: (1) all students who have combined visual and auditory impairments; (2) only deaf-blind students deemed to have academic and/or vocational "potential," with more seriously impaired students being served in programs for the severely or multiply handicapped; and (3) deaf-blind/multiply handicapped students whose educational needs cannot be met in categorical special education programs, including those for the visually impaired and the hearing impaired.

Several operational definitions of "deaf-blind" have been proposed to delineate more clearly those students in need of specialized services. The United States Office of Education (1975) defined deaf-blind students as:

> "...children and youth with...auditory and visual handicaps, the combination of which causes such severe communication and other developmental and learning problems that they cannot properly be accommodated in special education programs solely for the hearing handicapped child or the visually handicapped child" (p. 7415).

This definition does not clarify the extent to which a student's "severe communication and other developmental and learning problems" are caused by auditory and visual impairments, as opposed to other severe impairments, e.g., profound mental retardation (Orlansky, 1981). A person whose educational handicaps cannot be directly attributed to the multisensory impairment cannot technically be considered "deaf-blind".

McInnis and Treffry (1982) regard deaf-blind children and youth as multisensorially deprived and state that these students have "a combination of vision and hearing problems which prevent the use of either vision or hearing as a primary source of learning" (p. 267). Any learning problem therefore, can be attributed to the sensory impairments.

Because of the heterogeneity of the target population, Myers (1981) considers deaf-blind students to be those "with severe communication difficulties associated with defects of vision and hearing, often with other disabilities including, for many children, severe intellectual impairments and behavioral difficulties" (p. 44). The discriminating factor in Myers' definition is the need of deaf-blind students for specialized communication skills training. Myers feels that educators should look at the individualized educational requirements of the student, rather than the "label," when determining appropriate educational program placements.

Best (1975), Haring (1978), and Orlansky (1981) recommend that students be described in terms of their educational needs, rather than according to their disability. Sontag, Smith, and Sailor (1977) feel that labeling students has little educational value and propose that all of special education be divided into three broad categories: (1) general special education, for students needing instruction in remedial academics; (2) severely handicapped education, for students requiring an educational emphasis on basic skill development (e.g., self-help skills, communication skills, adaptive behavior, etc.); and (3) early education, for young students needing either basic skill instruction or pre-academic remediation. McDowell and Sontag (1977) underscore that "defining, labeling, and categorizing have little point unless they lead directly and specifically to appropriate placement and programming" (p. 4).

Deaf-blind students comprise a multihandicapped population, few of whom suffer from clear-cut deafness or blindness alone (Lowell, 1977; Maron, 1982). Even deaf-blind students whose educational program focus is academics can be considered severely handicapped, if they also require basic skill instruction (Bricker, 1978). The situation is more difficult because some predict that there will be a higher incidence of lower functioning, severely handicapped students needing service from the schools of the future (Hanley & Maher, 1980; Tweedie & Baud, 1981).

The educational behaviors and resource requirements which indicate that a student should be placed in a specialized program for the deaf-blind should be delineated. The needs of some deaf-blind students probably can be met through other placement, e.g., in a regular education program, a categorical special education program (including programs for the hearing impaired/multihandicapped and the visually impaired/multihandicapped), and/or a program for the severely/multiply handicapped. Whatever the primary placement of the individual student, consultative or augmentative services specific to deaf-blind education will be required (Orlansky, 1981).

EDUCATIONAL PROGRAMS FOR STUDENTS WHO ARE DEAF-BLIND

The potential of students who are deaf-blind is virtually undefined, as appropriate educational programs have only recently been provided them. Expectancies have often been set unjustifiably low in the past (e.g., deaf-blind/multihandicapped students "can't learn" or they "will never contribute to society"). Laski (1976) suggests that there is no such thing as an "ineducable" child and that all can benefit from education and training. Bijou and Cole (1975, p. 12) comment that "traditionally, an individual who does not learn what is presented is considered to be incapable, indifferent, unmotivated, or lacking" when what is actually lacking is an appropriate, functional educational program.

A disproportionate emphasis may also be placed on academic skills over more relevant basic life skills in an attempt to provide the student with an education commensurate to that received by other handicapped and non-handicapped populations. Best (1975) comments, "...far too many programs for the deaf-blind are academically oriented, and there are no jobs for the normal academician today, so what chance does a severely handicapped person have?" (p. 35).

A primary goal of education for deaf-blind children and youth should be to help each progress from some level of dependent functioning to levels of greater independent functioning (Sheuerman, 1976; Writer, 1979). The acquisition of skills that promote greater independence may be viewed in terms of environmental adaptation described by Sailor and Haring (1978) as "the process of arranging a relationship between the student and his or her environment that results in positive experiences for the

student and positive changes in skill acquisition" (p. 18). In order to attain this adaptive relationship, education must be viewed in non-traditional ways with program content being based on the needs of the individual student and the requirements imposed by the natural environments in which he or she lives, works, and plays (Hammer, 1975b; Robbins, 1977; Stein & Green, 1972; Writer, 1979).

Hatlen (1973) stresses the need for direct, concrete community experiences in every student's educational program and he pinpoints five long-term goals that he feels will result from such functional programming: (1) the attainment of the highest level of academic or other skill leading toward personal independence; (2) the development of a marketable vocational skill; (3) the ability to live as independently as possible in a community-based residence; (4) the opportunity to engage in satisfying social activities; and (5) the opportunity to gain satisfaction and enjoyment from recreational activities.

Best (1975) notes the need to plan for the deaf-blind student's post-school years and feels that an appropriate educational program should focus on the development of functional communication skills and positive interpersonal relationships. She proposes four primary areas of curricular emphasis: (1) self-actualization; (2) the development of human relationships; (3) economic efficiency; and (4) civic responsibility.

Laski (1976) states that deaf-blind persons have the same legal rights as nonhandicapped citizens, including: (1) the right to education, training, rehabilitation, and guidance to the extent that they enable the person to reach his or her maximum potential; (2) the right to economic security and a decent standard of living; and (3) the right to live in a family environment and to participate in different forms of community life.

Smithdas (1980), reflecting on the progress in educational practices used with children and youth who are deaf-blind, believes that community integration should be a goal for students, but that it will not be achieved unless educators teach students to make independent decisions. He states that "acceptance will only become a reality when we realize that service means assisting others to attain their goals--not supervision and direction of individual lives" (p. 1017).

Approaches to the Education of the Deaf-Blind

A systematic approach to education is necessary if deaf-blind students are to progress, but some controversy exists as to which direction that approach should take (Allen, 1978). Many educators try "new" approaches within their classrooms in an attempt to provide appropriate services for their students. This effort is usually undertaken prior to investigating the success or failure of similar approaches in programs of longer tenure than their own. The process of "re-inventing the wheel" is practiced too frequently by teachers of the deaf-blind.

Oppenheimer (1955) points out that "what is new is not new because it has never been there before, but because it has changed in quality" (p. 10). Hammer (1975a) states that many approaches "new" to deaf-blindness are actually "borrowed" from other fields (e.g., physical therapy, occupational therapy, psychology). He notes also that knowledge of a method does not automatically imply that a teacher can effectively apply that method with a group of students. He says, "...methods are not the answer. They are the vehicle to achieve the solution to the problem" (p. 4).

Four major curricular approaches are currently applied with children who are deaf-blind: (1) the traditional approach; (2) the developmental approach; (3) the behavioral approach; and (4) the community adaptation approach or criterion of ultimate functioning approach. The educator needs to become familiar with each approach and evaluate its quality in terms of the individual students he or she serves.

The traditional approach. The traditional approach places educational remediation (academics) as the top priority. The unique educational needs and/or chronological age of the student are rarely addressed in planning. The curriculum typically emphasizes the acquisition of basic preacademic skills a colors, numbers, and ABC's. Materials such as formboards, pegboards, and stacking disks (rings-on-a-post) are often used to teach concepts (Writer, 1981a). Even though the initial application of this approach may be both systematic and structured, the teaching of artificial, chronological age-inappropriate tasks in isolated situations does little to foster the student's independence.

Once it is determined that the student cannot learn under the traditional approach, the program frequently reverts to a preschool type of organization. The general philosophy is "if we 'love 'em and continue to say it loud enough, slow enough, and long enough, the students will begin to learn to the point that they could once again, perhaps, be exposed to a higher level of cognitive skills" (Burton, 1981, p. 76). Haring and Smith refer to such programs as "nurturing programs" which provide a loving atmosphere and cognitive experiences as opposed to structure.

The developmental approach. The developmental approach is based on child development theory and the presumed order in which children learn basic actions (Haring, 1979). This approach assumes an orderly progression through a series of developmental steps, stages, and/or curricular sequences. A Piagetian hierarchy of early developmental stages is frequently employed (Day, 1983).

Noonan and Reese (1984) question the assumptions of the developmental model when applied to students who are severely handicapped, noting that there is no empirical evidence to indicate which behaviors, "if any", are prerequisite to later skill acquisition. Hence, behavioral objectives based on this model may not be presumed to lead to functional skill development.

The behavioral approach. The behavioral approach requires that educational goals and objectives be determined through a detailed assessment of performance levels in specific areas of educational concern. The educator should have specialized skills in applying behavioral principles, establishing instructional conditions, employing measurement procedures, and arranging systematic instructional practices (Perske & Smith, 1977). "The behavioral view is that if the student does not learn, something is wrong or lacking in the training situation" (Bijou & Cole, 1975).

Noonan and Reese (1984) express reservations about the application of the behavioral model with students who have severe disabilities, because it does not provide a comprehensive approach for selecting instructional objectives. They caution that activities and procedures employed in this model might, consequently, be artificial and "severely controlling" to the extent that they preclude the generalization of skills learned to natural environments.

The community adaptation approach. The community adaptation approach, or "criterion of ultimate functioning" approach, stresses the teaching of skill clusters that prepare students for independence in socially, vocationally, and domestically integrated community environments (Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenwald, 1979; Brown, Nietupski, & Hamre-Nietupski, 1976; Burton, 1981; Haring, 1979; Orelove, 1978). This approach requires that the educator be able to visualize the independent function which will result from the completion of each segmental skill taught within a skill sequence (Sailor & Haring, 1978).

The community adaptation approach emphasizes the importance of teaching a skill in the context of the enviroment where it typically will occur (Bates, Renzaglia, & Wehman, 1981; Sternat, Messina, & Nietupski, 1977; Writer, 1979). Contextual instruction assists teachers to maximize instructional time through the integration of instructional and "caretaking" activities (McCormick, Cooper & Goldman, 1979). The use of natural settings for instruction also facilitates the generalization of skills across environments (Fieber, 1976; Gold & Rittenhouse, 1978; Orelove, 1978; Orlansky, 1979; Wilson, 1974).

Curricula based on this approach stress activities and materials that are both functional and appropriate to chronological age. Functional educational activities involve skills that are of immediate use to the student and employ teaching materials that are real rather than simulated (Allen, 1978; Bates, et al., 1981; & Brown, et al., 1979). Teaching students functional skills produces behavioral repertoires that maximize their adaptability and enhance their independence (Bricker, 1970).

Hanley and Maher (1980) underscore the need for educational services to extend beyond the classroom into the community in order to be meaningful for the student who is deaf-blind. The utilization of

chronological age-appropriate, community-based curricula offers a framework for instruction that is consistent with the philosophy of normalization and the desire to promote community participation of students (Gruenwald, Schroeder, & Yoder, 1982; Lehr & Brown, 1984).

Content of Educational Programs for Students Who Are Deaf-Blind

Deaf-blind students vary greatly in their skills and capabilities, hence, in their curricular needs. The performance requirements for increased independence in the student's current and future environments will also impact on the selection of curricular content. Deciding what to teach is ultimately the responsibility of the classroom teacher, in concordance with the opinions of the teaching/planning team (e.g., parents, teaching assistants, support personnel). Individual curricula must be based on "systematic and precise consideration of the unique circumstances and behaviors of the children the teacher is teaching" (Burton, 1981, p. 78).

Educational programs for students who are deaf-blind cover a wide variety of curricular domains ranging from basic skills to academics. Writer (1981a) describes seven content areas frequently addressed:

1. fine and gross motor-skill development (locomotion, postural control, purposeful use of hands);

2. sensorimotor skills (visual, auditory, tactual, vestibular, proprioceptive, and kinesthetic abilities);

3. communication and language skills (oral and non-oral abilities);

4. social skills (interactions with both handicapped and nonhandicapped peers and adults, interactions with the environment);

5. functional living skills (self-care activities, domestic skills, functional academics, independent travel, community functioning);

6. recreation and leisure skills; and

7. vocational skills.

Research studies with deaf-blind subjects were identified in each of the major areas, with the exceptions of fine and gross motor skill development and vocational skills. The preponderance examined sensorimotor skills and communication skills, which is in concordance with the findings of Blea and Overback (1977). Studies ranged from ones that employed real-life objects and events in natural environments to others that employed artificial materials in simulated or isolated situations.

Research on sensorimotor skills. Several authors report techniques and procedures outside the context of empirical studies. Cress, Johnson, Spellman, Sizemore, and Shores (1982), and Cress, Spellman, DeBriere, Sizemore, Northam, and Johnson (1981) discuss methods for visual assessment and stimulation, visual acuity testing, and vision screening respectively. Ficociello (1976) describes visual stimulation techniques designed to enhance the use of residual vision by children who are deaf-blind as the result of maternal rubella.

Utley, Duncan, Strain and Scanlon (1983) trained sensory impaired/multihandicapped students to fixate on both blinking Christmas tree lights and a dim night light. Initial fixation was a more reliable indicator of task performance than sustained fixation and the authors stress the need for active responses, rather than passive or stereotypical responses, as behavioral indicators. Implications for use of the acquired visual fixation skills in the development of augmentative communication systems (communication boards) are discussed.

Silva, Knight, and Friedlander (1973) observed the ability of deaf-blind, post-rubella children to track a light across a darkened room. They recorded three times more headturns by their subjects toward the light in the test situation than during the "no light" situation in a darkened room. The authors conclude that the subjects did make a behavioral connection between visual perception and head movement.

Potenski (1983) utilized a black light to train deaf-blind/multihandicapped children and youth to perform a shape discrimination task. A white four-piece formboard with flourescent shapes and holes was employed in the experimental procedure. All of Potenski's subjects performed significantly better under black light than under a normal light. He discusses the importance of visual stimulation in the promotion of environmental exploration and stressed the "stimulation value" of the instructional materials as a way to facilitate active exploration.

Kershman and Napier (1982) developed systematic procedures for eliciting and recording responses to auditory stimuli in children who are deaf-blind/multihandicapped. They employed a three phase procedure to: (1) record spontaneous responses to naturally occurring environmental stimuli; (2) collect data through systematic observation of responses to calibrated sound sources and toys; and (3) summarize data findings. The authors conclude that their auditory acuity measure is appropriate for pinpointing the starting place for auditory training with individual students. Cooperation between teachers, teacher aides, parents, and therapists was enhanced during the study and they deduce that this procedure could assist parents and teachers in focusing on the auditory environment of both home and school.

In longitudinal observations of the auditory response patterns of young deaf-blind children, Franklin (1979) noted that when speech, music, and sound toys were systematically presented to the children, the majority demonstrated lower thresholds for speech than for the other sounds. She concludes that speech band audiometric techniques have potential benefits for the threshold testing of deaf-blind children.

Alberto, Troutman, and Briggs (1983) used negative reinforcement (removal of an ice cube from the palm of a deaf-blind child's hand) to condition head turning toward the source of blowing air. Once the targeted behavior was established, the source of stimulation was switched from a fan to air blown from an adults' mouth onto the subjects' cheek. The potential for shaping the acquired response to the activation of an electric fan as a leisure activity was discussed.

Research on communication skills. Considerable information has been generated on methods for developing communication skill in students who are deaf-blind. A common theme addresses the need for functionality in both program planning and implementation.

Beginning communication skills need to be taught in natural situations and contexts, as deaf-blind students may not be able to make the abstract associations required of artificial or simulated situations (Fieber, 1976). Guldager (1969) stressed relevancy by emphasizing the use of real-life objects and situations; "...when building language and experiences for the deaf-blind child, one must use real things, situations from the childs' world, not imitations or situations...to which the child cannot relate" (p. 205).

A "reactive" environment should be created for the deaf-blind child so the child is motivated "...to begin and continue the activities and to reach beyond himself and gain satisfaction from the world around him" (McInnis & Treffry, 1982, p. 25). Three levels of student involvement in the natural environment were noted: (1) co-active (paired movements with another person); (2) co-operative (shared movements with another person); and (3) reactive (independently initiated interactions with other persons and the environment).

"Functional competence" should be a major consideration in the development of communication skills (Goetz, Schuler & Sailor, 1981). Functional responses (p. 52) are described as ones that: (1) produce an immediate consequence for the child; (2) are potentially reinforcing; (3) are specific to the response; and (4) are natural to the child's interaction with the environment. The authors stress the need for students to have both reason and motivation to use the symbols acquired in natural contexts.

Eight functional signs were taught to deaf-blind students using a task analysis format to delineate the component parts of each sign prior to

instruction (Gold and Rittenhouse, 1978). Physical assistance was faded as individual subjects acquired competence in sign production and the signs were taught in natural contexts throughout. The performance criterion utilized was the spontaneous production of the sign outside of training situations.

Bowling (1979) taught a child a combination of signs and fingerspelling by the use of simultaneous communication throughout instruction. The student first imitated the signs employed by her teacher, then produced them spontaneously. The first signs the student independently generated were ones that she had seen used repeatedly in natural contexts.

Clark and Cox (1976) increased the quantity of verbal communication skills in a deaf-blind child through the simultaneous reduction of his self-abusive behavior. The mother of the student participated in a classroom training program that included: (1) reading selected material on behavioral analysis; (2) observing and recording data on the behavior of a student other than her son; and (3) assisting the teacher in the instruction of her son. A home intervention program was subsequently instituted utilizing techniques learned in the classroom. The authors conclude that parents "can learn how to control their child's behavior and, perhaps more importantly, how not to be controlled by it" (p. 75).

Reed, Doherty, Braida, and Durlach (1982) investigated the effectiveness of the Tadoma method of speech comprehension with nonhandicapped adult subjects who simulated deafness and blindness. Each subject alternated as "speaker" and "reader" during two consecutive experiments that required subjects to read first consonant and vowel sounds, then sentences from a known, fixed vocabulary. Experienced Tadoma users relied on their "tactile vocabulary" and their ability to comprehend connected speech to attain a 40% accuracy rating in sentence comprehension. A highly motivated individual may be able to follow conversational speech through use of the Tadoma method after (roughly) two to three years of practice.

Griffith, Robinson, and Panagos (1983) had thirteen blind subjects rate eight functional signs on their tactile iconicity (the relationship between how the sign felt and the word it represented). From comparing the ratings of the blind subjects with the ratings of sighted subjects, the authors conclude that the iconic qualities of the signs were the same, whether perceived through sight or through touch. They recommend that the first sign vocabulary for a deaf-blind student should be based upon iconic signs that have meaning for that student.

Jensema (1981a,b,c,d) reported on a national survey of communication methods used by 195 teachers and their deaf-blind students. Each teacher provided data on one of his or her randomly selected students. The teachers in the sample primarily used the same communication methods in

the classroom as they typically used in social situations, i.e., speech. The students primarily used manual methods of communication that included both signs and gestures. The students' visual and auditory losses, their IQ scores, and their etiologies had only a small bearing on the communication method employed. Students with severe to profound vision losses chose tactile modes of communication over visual ones. Students with high rates of stereotypy used manual communication modes more frequently than did students with low rates. The author concluded that, since deaf-blind children prefer manual modes of communication, their teachers should employ these concurrent with speech.

Research on social skills. Only two studies were identified that investigated aspects of deaf-blind students' social behavior. Barton and Logrow (1982) employed an overcorrection procedure to reduce the self-injurious and aggressive behavior of two children and one youth who were deaf-blind. The procedure was equally effective in reducing the undesired behavior carried out over the whole day or during only part of the day. The need for personnel to receive specialized training in the appropriate application of aversive procedures was noted.

Love (1983) surveyed parental and staff attitudes toward instruction in human sexuality for sensorially impaired students at the Alabama Institute for the Deaf and Blind. Mothers were most likely to complete the questionnaire. Ninty-three percent of the parents wanted their son or daughter to receive training in human sexuality, but less than 50% of the staff felt qualified to provide that training. The topics that both staff and parents rated as top priorities for instruction were: (1) sexual cleanliness; (2) own human body; (3) venereal disease; (4) dating; (5) reproduction; (6) pregnancy; (7) marriage; and (8) feelings about self and others. Although both parents and staff expressed a fear of the subject, they recognized that knowledge about human sexuality was essential to the students' education.

Research on functional living skills. Opdahl and Whitehead (1976) described a backward chaining technique to teach dressing skills to a deaf-blind child. A combination of home and school instruction was employed during the ten-week skill acquisition period. Maintenance of the skill in the home environment was evident after eleven months.

Research on recreation and leisure skills. Knight (1971) studied group recreational activities deemed worthwhile by multihandicapped blind children. The author noted, "...almost every child had to some degree: a lack of confidence in themselves, a pervasive attitude of inadequacy and bewilderment" (p. 52). The activity selected--the production of a "radio show" that included music and sound effects--evoked an increase in students' feelings of self-worth and self-confidence.

Hamre-Nietupski, Nietupski, Sandvig, Sandvig and Ayres, (1984) described a program to provide two deaf-blind young adults with an age-appropriate leisure skill to use in their community living units. The operation of a cassette tape recorder was selected based upon the following considerations: (1) the need to provide opportunities for appropriate sensory input; (2) the need for materials having minimal motor requirements for performance; and (3) the need for materials that did not require a rapid response. Both students acquired the targeted skill. The authors postulate that the three criteria used in the selection of the cassette recorder can be applied to the selection of leisure activities for other students who are deaf-blind.

PROVISION OF EDUCATIONAL SERVICES TO DEAF-BLIND STUDENTS

A deaf-blind individual is handicapped in all situations and on a 24-hour basis. Thus, the educational curriculum should reflect the needs and ancillary services required by students in all situations (Crowner, 1979). The optimum delivery of educational services necessitates that instructional time be spent in both school and non-school environments (Freagon, 1982; Hanley, 1980; Hamre-Nietupski, Nietupski, Bates, & Maurer, 1982; and McCormack & Audette, 1977). Effective community integration of deaf-blind students also requires that they be afforded multiple opportunities for social interactions with non-handicapped peers and adults across extended educational environments (Bettica, 1979; Perske & Smith, 1977; Stainback & Stainback, 1983).

Most students who are deaf-blind are handicapped throughout their lives. They require educational and/or training experiences that continue from birth until old age. (Best, 1977; Cotten, Long, & Askew, 1979; Hicks & Hicks, 1981; Cotten & Wade, 1984). Hence, the need exists for early intervention and service continuation beyond the age of 21.

The disabilities experienced by the child who is deaf-blind can interfere significantly with his or her development from birth (Perske & Smith, 1977). Programming initiated immediately after a child has been identified as having a handicap can serve to prevent secondary or cumulative handicaps (Allen, 1978; Brown et al., 1977).

A delay of several years between identification and educational intervention impedes management of the developmental problems when they are least complex (Iacino & Bricker, 1977). Early intervention can reduce the effects of handicapping conditions that, if left untreated until three to five years of age, can result in the necessity for institutional or other custodial care in adulthood (Appell, 1977; Dolan, 1972; Haring, 1977; Vincent, Salisbury, Walter, Brown, Gruenwald, & Powers, 1980).

The deaf-blind person who depends on others for assistance with basic life skills requires a continuation of services beyond the age of 21. Cotten and Wade, (1984), Hicks & Hicks (1981), and Ouellette (1984a, b) emphasize the need for educators and rehabilitation personnel to work cooperatively in the development of a continuum for students age 16 through adulthood. Smith (1984) also stresses the need for alternative community residential environments. She expresses a parent's concern for the future of her son: "...we need to know that our children will have a place for themselves within a minimal, but restricted, environment...Our children will require substantial maintenance, rehabilitation, and supervision for the remainder of their lives" (p. 3).

Educators should focus on developing a students' "readiness for work," rather than focusing on isolated job tasks and should maximize community-based instruction to prepare the student for a life style away from the school setting (Bettica, 1979). Cotten, et al., (1979) outline a continuum of services for deaf-blind indivduals extending from birth through adulthood and emphasize the "right to risk" in preparation for independence. "...Students should be given the freedom to grow, to test their limits, and to risk failure" (p. 744).

Vadasy and Fewell (1984) studied predictions about the future residential and vocational placements for a group of fifteen deaf-blind youth who were receiving services in a residential setting. The predictions of the students' mothers were compared to the predictions of a state coordinator of deaf-blind services who was familiar with most of the students' educational performance. Eighty-seven percent (N=13) of the mothers agreed with the coordinator's predictions for residential placement. The two mothers who disagreed felt that their child required a more restricted living arrangement. Sixty percent (N=9) of the mothers disagreed with the coordinator's predictions for vocational placement. All felt that their child required a more restricted vocational placement. The authors postulate that the discrepancies in opinion could be due to many factors, including: (1) a lack of familarity by the mothers with the vocational and residential options available; and (2) a lack of familiarity by the coordinator with the students, i.e., the coordinator may have been forcasting the "ideal" option, rather than the realistic one.

Freagon (1982) studied educators' perceptions of the minimum requirements for an effective continuum of education, residential and vocational services to persons who are handicapped. Thirty-two graduate students enrolled in a methods course in the area of severely handicapped were surveyed of whom 88% were practicing teachers. Respondents felt the following to be minimal acceptable standards for services.

1. Educational Continuum: placement in a self-contained class on an age-appropriate regular school site rather than placement in a regular class.

2. Residential Continuum: placement in a group home having eight or less residents in a middle-income neighborhood rather than independent community living.

3. Vocational Continuum: opportunity to engage in gainful employment in the community with back-up support provided rather than employment without back-up support.

Team Approaches to Educational Service Delivery

There is no one way to teach "the deaf-blind" as each student is unique. A multiplicity of techniques and procedures must be used if the needs of individual students are to be met. The more severely handicapped the student, the more frequent the occurrence of multiple disabilities that necessitate intervention by a variety of personnel, programs and agencies. The planning, management, and delivery of these services cannot be done by teachers alone; a team approach is required (Iacino & Bricker, 1978; Umbreit, Karlan, York, & Haring, 1980).

A team approach necessitates joint participation by many individuals, including the student's teacher, teacher aides, parents, and all other persons who provide direct services to that student (Lyon & Lyon, 1980). Often physical therapists, occupational therapists, speech and language specialists, social workers, counselors, vision specialists, hearing specialists, psychologists, diagnosticians, rehabilitation personnel, physicians, and nurses are also needed (Hammer, 1977; Hart, 1977a; Sears, 1981; Writer, 1981a).

The parents of the deaf-blind student can be the most important members of the teaching team (Schliefer, 1979). Children and youth who are deaf-blind spend more of their lives at home than at school. Therefore, educators and parents work cooperatively in all aspects of program planning and implementation, if instruction is to generalize beyond the school environment (Bates et al., 1981; Filler & Krasari, 1981; McLoughlin, 1981; Sailor & Haring, 1977). Perske and Smith (1977) states that, "...an hour of teacher-child instruction, coupled with an hour of parent-child reinforcement of that instruction, is more effective and efficient by a twofold measure than is a straight two hours of teacher-child instruction with no parent reinforcement" (p. 21).

A truly exemplary program is one that includes the total family in the development of a consistent and comprehensive 24-hour course of instruction.

In work with deaf-blind students three team approaches have been applied most frequently during the last decade: (1) the multidisciplinary team; (2) the interdisciplinary team; and (3) the transdisciplinary team.

The multidisciplinary team approach. The multidisciplinary approach evolved from the medical model. Persons from various disciplines evaluate a patient and then formulate separate recommendations as to treatment (Perske & Smith, 1977). In the school settings individual assessments of the student are made at different times and places, usually outside the classroom, home, and/or community environments. The information derived is usually passed along to one person, i.e., the teacher, who is then responsible for the interpretation and implementation of services. The value of this procedure, therefore, depends on the expertise and educational philosophy of the one person receiving the information (Hart, 1977a).

The parallel practice to removing the student from the classroom for evaluation, without involving the teacher, is the isolated therapy model (Sternat et al., 1977). Therapy is provided in environments other than those in which the student generally functions, as, for example in providing communication therapy in the speech therapist's office.

The interdisciplinary team approach. The interdisciplinary approach utilizes the same team members as the multidisciplinary approach with evaluation and treatment services, again, provided in environments unfamiliar to the individual student. The difference between the two is that the latter advocates (1) formal communication between disciplines; and (2) the assignment of a case manager to coordinate services in an effort to reduce compartmentalization and fragmentation of the program (McCormick & Goldman, 1979).

Members of the interdisciplinary team meet together to share findings, make recommendations, and develop an educational plan. Perske and Smith (1977) caution that "...often team recommendations may be more ideal than practical because they are based on isolated views of the child, not on his day-to-day functioning in the classroom" (p. 17).

The transdisciplinary team approach. The transdisciplinary team approach involves all disciplines working cooperatively in the design of educational programs with implementation carried out by one or two team members. It requires that team members exchange information and skills across traditional disciplinary lines (Crowner, 1979; Hammer, 1977; Lyon & Lyon, 1980).

Perske and Smith (1977) state, "...role release permits that training and authorization to carry out a particular specialty function can be given to others: to the teacher, to a paraprofessional, or to a parent" (p. 17). Service delivery is thus handled by the persons who are closest to the student (e.g., teachers and parents), while other members of the team provide consultative back-up (Sailor & Guess, 1983). All assessment and implementation procedures are executed within environments where the student is most frequently called upon to perform (i.e., in the classroom, home, and community).

Parallel to the transdisciplinary approach is the integrated therapy model, whereby assessment and therapy are implemented in the classroom and home environments (Orelove, 1978). The therapist is involved in an inservice role, training teachers, aides, and parents how to integrate therapeutic activities into the ongoing daily routine (Bates et al., 1981).

The effective implementation of the transdisciplinary approach requires that sharing professionals re-think their own functions and goals (Hammer, 1977). He stresses the overall educational advantages of this approach for deaf-blind students: "By giving we receive, and in the end the child benefits. That is the goal shared by us all" (p. 4).

Location of Programs for the Deaf-Blind

Public Law (P.L.) 94-142 mandates that all handicapped students be served in the least restrictive environment. Brown, Wilcox, Sontag, Vincent, Dodd and Gruenwald interpret this to mean that the educational service models used for handicapped students "...must closely approximate the best available service delivery models used for nonhandicapped students" (p. 196).

Each deaf-blind student's unique educational needs should be the major consideration in program placement (Flathouse, 1979). Murray (1981) agrees that individual learning and living needs are priority factors in program placement, but notes that they are not the only factors. She feels the family's needs, community and peer attitudes, and the environment itself should all be considered when determining the least restrictive educational placement. The least restrictive environment for one student, therefore, might be a public school classroom; for a different student it might be a residential training program.

The continuum of services available at the National Center for Deaf-Blind Youth and Adults facilitates the transition from "education in childhood to rehabilitation in adulthood" (Dantona & Salmon, 1972). Ouellette (1984a) proposes that a model living community be developed for deaf-blind persons over the age of sixteen to assist their transition from educational to rehabiliation services.

School programs for deaf-blind children and youth have begun to move from clustered or segregated school sites to dispersed or integrated sites on regular school campuses (Orlansky, 1981). This shift is primarily due to efforts by the schools to comply with the concept of "least restrictive environment" specified in P.L. 94-142. Among the aspects of clustered schools that are discordant with this concept are (1) they tend to stress "handicapped" skills, attitudes and values; (2) they generate little need for longitudinal transition plans; and (3) they offer limited possibilities for integration into community life and normalization (Brown, Ford, Nisbet, Sweet, Donnellan & Gruenwald, 1983; Brown et al., 1977; Sailor & Guess, 1983).

Wehman and Hill (1982) and Brown et al., (1983) see opportunities for interactions with nonhandicapped peers as a major advantage of dispersal models. They stress the importance of placing students on regular school sites with nonhandicapped students of the same chronological age. They believe positive interactions with age-level nonhandicapped peers will promote attitudes, skills, and values that will enable both groups to be sharing, participating members of post-school communities.

A "side-by-side" dispersal model for the delivery of services (Thomason & Arkell, 1980) involves the grouping of at least two classrooms for deaf-blind students on the same regular school campus. The advantages of this model are: (1) the promotion of more normalized instructional objectives; (2) the facilitation of inservice training; (3) the promotion of an integrated therapy approach; and (4) a reduction in feelings of isolation often experienced by teachers who have the only classroom for deaf-blind students on a site.

EDUCATIONAL ASSESSMENT OF DEAF-BLIND STUDENTS

Educational assessment identifies a student's strengths and weaknesses in a way that has direct application to the development of an individualized course of instruction (Bricker, 1979; Robbins, 1977). Calvert, Reddell, Jacobs, and Baltzer (1972) view the processes of educational assessment and educational programming as inseparable.

The student's classroom teacher is the key member of the assessment team (Sailor & Haring, 1977). The teacher should be the principal evaluator, since he or she is the person most familiar with the student's typical behavior across critical areas of educational concern (Langley, 1979). All persons involved in the assessment process should have first-hand knowledge of the student's spontaneous behavior in natural environments (Sims-Tucker, 1979). Assessment team members might, therefore, consist of (1) the classroom teacher; (2) the teacher aides in the classroom; (3) the parents of the student; and (4) support staff who have worked with the student and observed his or her behavior over time.

The use of standardized tests with children and youth who are deaf-blind has been widely criticized (Bennett, Hughes, & Hughes, 1979; Calvert et al., 1972; Simenson, Huntington, & Parse, 1980; Stewart, 1977; Vincent et al., 1980). Stewart (1977) challenges the efficacy of comparing scores achieved by handicapped students with those of nonhandicapped populations. He also questions the feasibility of assessing deaf-blind students in any way comparable to the assessment of students who have either vision or hearing handicap. The multiplicity of the handicaps (sensory, cognitive, orthopedic, behavioral) frequently manifested by deaf-blind children and youth make the use of a majority of standardized tests invalid (Bennett et al., 1979). Langley (1979), and Murray and Wright (1979) feel that inappropriate, formal assessment

procedures are often used; evaluators are either (1) inexperienced in the assessment of multihandicapped students; or, (2) unaware of more appropriate, informal assessment procedures.

Simenson et al., (1980) recognize the value of some informal assessment tools currently available (Writer, 1981b; 1984), but challenge the appropriateness of others for students who are deaf-blind. They feel that (1) many of the domains addresssed are not relevant; and (2) many of the items, designed to measure the behavior of infants and preschool students, "penalize" older students for not performing what are artificial, age-inappropriate tasks. Criterion-referenced tools offer a viable alternative to developmental tests, but few have items that are appropriate for a deaf-blind student over the age of twelve.

No one assessment instrument is capable of providing all of the information required about any given student (DuBose, Langley, & Stagg 1977; Sims-Tucker 1979. Simenson et al., (1980) stress the importance of using multiple procedures that are capable of identifying critical areas of ability and educational need, rather than merely generating a questionable score. Calvert et al. (1972) recommend the development of a behavioral profile based on observations of the student in school and home environments and on a parent interview. Day (1983) and Stewart (1977) also stress the importance of observing the students' performance with familiar persons in natural environments.

Falvey, Rosenberg, and Grenot-Scheyer (1983) and Gruenwald et al., (1982) recommend an ecological inventory of the student's home and community environments to pinpoint skills requisite for increased independence across four domains: (1) domestic; (2) recreation and leisure; (3) vocational; and (4) community functioning. Current and future natural environments in which the student is/will be are identified and the major activities that occur in each are listed. Those activities that the individual can and cannot do are subsequently identified. A prioritization of the skill areas to be worked on is based on data generated from (1) an interview of the student's parents or guardians; and (2) observation of the student's current level of skill performance in the natural environments.

The ecological inventory process is a practical means for assessing a student's strengths and weaknesses in critical skill areas that are directly related to functional performance in non-school environments (Brown, Nisbet, Ford, Sweet, Shiraga, York, & Loomis, 1983; Sailor & Guess, 1983; Wehman & Hill, 1982). The results of the assessment should lead to the development of a community-based program of instruction.

Research in the Area of Assessment

Studies on the assessment of deaf-blind children and youth compared the teladiagnostic videotape protocol (Curtis & Donlon, 1984; Curtis et

al., 1975; Tweedie, 1974) and its effectiveness as a measure of student performance with developmental assessment tools (Diebold, Curtis, & DuBose 1978a, b). Research on the evaluation of deaf-blind adults (Search, 1974) was identified in the literature search, but no additional empirical studies on the assessment of school-age children was found.

Tweedie (1974) utilized a systematic observation technique to assess the performance of a deaf-blind student in four different instructional settings: (1) unstructured activities; (2) structured tasks; (3) response to sensory stimuli; and (4) interpersonal interactions. The student's behavior was videotaped and a comparison was made between his performance in 1969 and his performance in 1973. The student made positive gains over the four-year interval. Tweedie suggests that the use of videotapes in assessment is an effective tool for demonstrating behavioral change in students whose progress is typically slow.

Curtis et al., (1975) employed videotape observation to investigate discret behavior in deaf-blind students. Each student's performance was evaluated by multiple observers using the teladiagnostic protocol rating scale. The following major conclusions were drawn.

1. The majority of learning was conducted through tactile-motor pathways.

2. The poorest instructional arrangement for learning was the structured task situation.

3. Vision was considered to be an asset in a majority of students.

4. Tactile-kinesthetic and tactile-motor sensory and expressive avenues are superior means of communication.

5. A greater emphasis needs to be placed on recreation and leisure skills.

6. Instruction needs to take place in contextual situations.

7. There needs to be more exposure to problem solving situations across daily tasks.

8. There needs to be more opportunities for interaction with nonhandicapped peers.

In a ten-year follow-up on those students, thirty-seven of the forty-nine students evaluated in 1973 were located (Curtis & Donlon, 1984). Only seventeen were identified in the National Registry of Deaf-Blind Children, although all were included in the Registry in 1973. Both long-term planning and follow-up for all identified deaf-blind students are needed.

Diebold et al., (1978a, b) investigated the relationship between psychometric and observational measures of performance in deaf-blind children and youth. The results of the teladiagnostic videotape protocol were compared with the results of six different tests: (1) Cattell Infant Intelligence Scale; (2) Stanford-Binet Intelligence Scale; (3) Maxfield-Buchholz Scale of Social Maturity for the Blind; (4) Peabody Motor Scales, (5) Receptive-Expressive Emergent Language Scale (REEL); and (6) Preschool Language Scale. A correlation, but not a linear relationship, was found between the results of the two procedures. The developmental tests tended to rate the students as "lower functioning and nonvariable" from measure to measure, and the teladiagnostic protocol tended to rate the students as "higher functioning and more variable." The authors conclude that a combination of systematic observation and developmental assessment should be used to evaluate deaf-blind students.

Program Evaluation

Tweedie and Hicks (1977) recommend that educational programs for deaf-blind students be evaluated quarterly by outside experts (i.e., third party evaluators). They advocate a flexible rather than standardized program evaluation that makes individual student change over time the major indicator of program effectiveness.

Sailor and Haring (1977) suggest that all aspects of the instructional environment be evaluated including (1) the student; (2) the classroom; (3) the teaching staff; (4) educational administrative considerations; and (5) the total educational ecology. Brown et al., (1983) feel that the location of instruction is also a factor in evaluating program effectiveness and offer a continuum of four options from most restrictive to least restrictive for consideration: (1) instruction in classroom only; (2) instruction in classroom, then in community; (3) instruction in classroom and community; and (4) instruction in community only. The authors recommend that a majority of instruction take place in the community if students are to be optimally prepared for post-school experiences.

A different approach to program evaluation is to identify those factors that indicate an ineffectual program. These can serve as "red flags" to alert the evaluator to areas of concern. Brown, Pumpian Baumgart, Vandeventer, Ford, Nisbet, Schroeder, and Gruenwald (1981) list seven major contributors to poor quality educational programs.

1. Untrained or undertrained teachers.

2. Inadequate inservice training of staff.

3. Training of students in segregated environments away from nonhandicapped peers.

4. Educational focus on in-school instruction rather than community-based instruction.

5. Curricula that focus on skills required of students under five years of age.

6. Lack of parent involvement.

7. Lack of focus on independence in non-school and post-school environments.

PREPARATION OF TEACHERS TO SERVE DEAF-BLIND STUDENTS

Personnel preparation programs for teaching deaf-blind/multihandicapped students received momentum in the mid-1970's, as increasing numbers of trained educators were required to meet the needs of previously unserved students (Thomas, 1980). By 1978 there were 113 university and college personnel preparation programs in the combined areas of severely handicapped (SH) and multihandicapped (MH) (ERIC Clearinghouse, 1978). Ninety-five programs offered graduate training in SH and MH education, while 48 programs offered advanced or state certification in these areas.

Program expansion reached its peak around 1980, when reductions in teacher training programs occurred. The 1983 National Directory of Special Education Teacher Preparation Programs reported 100 university and college preparation programs in the combined areas of SH and MH. Seventy-three programs offered graduate training, while 27 programs offered undergraduate training. Sixteen programs offered training in MH and 84 programs offered training in SH. Nineteen states reported no personnel preparation programs in either SH or MH.

The Regional Centers for Services to Deaf-Blind Children (Programs for the Deaf-Blind, 1982) reported 38 graduates from eight teacher training programs in 1982. There were only nine graduates from four training programs reported in 1983 (Programs for the Deaf-Blind, 1983). This reduction in specially trained personnel occurs at a time when increasing numbers of deaf-blind children are being identified and few trained personnel are prepared to serve them.

Writer (1981a) surveyed teachers of the deaf-blind/multihandicapped in 14 states, Puerto Rico and the Virgin Islands. Only 4.9% of the respondents reported a degree concentration in deaf-blind education. An additional 9.9% reported a degree major in MH, and 17.3% reported a major in SH. The remainder of the teachers reported training in categorical special education. There were more respondents trained in mental retardation (49.4%) than in any other area.

Teachers of deaf-blind children and youth require skills and information different from those required by teachers of students who are more mildly handicapped. The program focus needs to be on the development of skills beyond traditional academics (Hart, 1977). Teachers of the deaf-blind should be prepared to toilet train students, teach eating skills, manage specific behavior problems, utilize and train augmentative communication skills, design and implement community-based training programs, teach functional recreation and leisure skills, execute comprehensive educational assessments, manage acute health problems, and engage in a variety of educational activities not typically encountered in traditional categorical special education programs. These teachers must receive specialized training on techniques and procedures for children and youth who have multiple disabilities; no combination of categorical areas of preparation will suffice (Flathouse, 1982; Hart, 1977a, b; Lennan, 1982; Mira & Hoffman, 1974; Tweedie & Shroyer, 1982).

The teacher of students with severe/multiple disabilities should be a synthesizer with the ability to gather information from a variety of specialists and incorporate it into effective classroom strategies (Bricker, 1976). The teacher "synthesizer" should also be able to arrange educational environments, identify and/or design instructional materials, apply adapted equipment, measure small increments of behavioral change, identify and utilize educational resources that exist outside their immediate educational program, and serve as an educational facilitator and resource to the families of deaf-blind students (Hart, 1977a, b; Iacino & Bricker, 1978; Writer, 1981a). Sontag, Burke, and York (1976) summarized, "...there is a direct relationship between the level of the student's disability and the competencies of the teacher, i.e., the more pronounced the level of disability, the more specific and precise are the competencies required of the teachers" (p. 22).

Unfortunately, most classrooms for the deaf-blind are staffed with untrained or inappropriately trained teachers (Gubser, 1980; Hart, 1977b; Lennan, 1982; Scandary, 1979; Tweedie & Shroyer, 1982). Currently, zero training is a fact of life in many classrooms for the multihandicapped, zero training in the sense that those persons responsible for the provision of services to students have received little or no training pertinent to their job (Burton & Hirshoren, 1979).

Preservice and Inservice Training Required by Teachers of Deaf-Blind

There is general agreement that, if the efficacy of teacher preparation is to be demonstrated, such preparation should be competency-based (Haring, 1979). Wilcox (1977) defined competency-based teacher education as "any program which is defined by statements of trainee performance" (p. 418).

Teacher competence may be divided into the sub-categories of informational competence and performance competence. An informational competency is one that specifies the information that must be acquired in order to achieve performance competency (Umbreit et al., 1980). Performance competency is a set of behaviors a teacher engages in that results in empirically verifiable changes in the behavioral repertoires of students (Brown & York, 1974).

A variety of strategies are commonly employed in the generation of competency statements. A majority of competencies have been determined largely by expert opinion rather than by analysis of teacher behavior (Bricker, 1976; Umbreit et al., 1980). Verification of competencies by practicing teachers would be a step beyond the generation of program competencies by "experts" (Wilcox, 1977).

Writer (1981a) surveyed the training received and needed by teachers of deaf-blind/severely multihandicapped (DB/SH) Students. The 133 areas of training addressed were derived from a combination of literature review and information provided by experienced educators of deaf-blind/severely multihandicapped (DB/SMH) children and youth.

Practicing teachers with 1 to 15 years experience serving DB/SMH populations rated each item in terms of: (1) its usefulness in daily instruction; (2) its importance in the preservice training of future educators; and (3) its relevance to the respondent's current inservice training needs. One hundred and two areas of training were considered to be highly useful by teachers in fulfilling the ongoing responsibilities of their jobs. Areas having a mean score in the top 30% of all items were contained within thirteen major categories. The top six categories in rank order of <u>usefulness</u> were:

1. behavioral technology;
2. classroom organization and management;
3. interdisciplinary cooperation;
4. motor skill development;
5. educational foundations (for DB/SMH); and
6. instructional techniques.

Each of the 133 areas addressed on the questionnaire was considered a necessary component for teacher preparation. The top six priority categories of <u>training</u> were:

1. behavioral technology;
2. classroom organization and management;
3. motor skill development;
4. health management;
5. interdisciplinary cooperation; and
6. curriculum development.

Fifty-five areas were identified as being priority inservice training needs. Areas in the top 20% were subsumed within 13 major categories. The top six categories were:

1. educational foundations (for DB/SMH);
2. health management;
3. motor skills development;
4. interdisciplinary cooperation;
5. sensory-perceptual development; and
6. instructional techniques.

Writer (1981a) derived what could potentially serve as core competencies of preservice training programs for educators of the DB/SMH by combining (1, the items considered to be most useful by respondents; and (2) the items respondents considered to be most essential to the training of all teachers of students who are DB/SMH. The need for SMH education to be a specialized (i.e., separate or supplementary) area of special education teacher preparation was affirmed by 96.2% of the educators surveyed. This need was corroborated by further investigation of the attitudes of respondents toward the adequacy of their preservice training. Educators with specialized training in DB/SMH education considered their preservice training to be adequate preparation for fulfilling the responsibilities of their current teaching assignment. Educators with categorical special education training considered their preservice education to be inadequate preparation. The difference between the attitudes of the two groups was significant at the .006 level.

A follow-up study by Writer and Wagner (1985) surveyed 218 California educators of DB/MH students to determine their priority inservice training needs. The 51 areas of training addressed were derived from a combination of research (Writer, 1981a), literature review, and information provided by experienced educators of DB/MH children and youth.

Each of the 51 training areas included in the survey instrument was considered by respondents a priority area needing inservice training. The top items were contained within six categories, or skill clusters:

1. communication skill development;
2. development of naturalized curricula that promote functional skills;
3. development of functional, transferable vocational skills.
4. promotion of positive social interactions between students and others;
5. development and implementation of functional instructional techniques;
6. application of functional educational asessment procedures.

Teacher training programs will never truly be competency-based until it is verified that the acquisition of certain informational and performance competencies does produce positive, observable changes in the behavior of students (Umbreit et al., 1980). Sontag et al., (1976) suggest that teacher competencies are directly related to the instructional problems and acquisition deficits presented by students (i.e., if the students are non-oral, the teacher must be able to train them to speak and/or employ augmentative communication modes). Further investigation of teacher performance and student performance in actual classroom and community situations remains to be made before the preservice and inservice training required by educators of deaf-blind students can be decided.

SUMMARY AND DISCUSSION

Much has been written on methods and procedures deemed appropriate for children and youth who are deaf-blind, but little is empirically based. There is a preponderance of narrative in the literature that describes purported "best practices", with scant justification offered to support their application. Some studies that do employ a research design generate information of limited utility to educators in the field (e.g., verification that deaf-blind children with congenital rubella syndrome will visually localize to light).

Blea and Overbeck (1977) refer to the "data lag" that exists in the field of deaf-blind education. This lag is most evident when quality educational practices within classrooms for the deaf-blind are compared to procedures written about in current literature. It is not uncommon for a "new and promising" technique to be one that experienced educators had abandoned as ineffectual five or ten years before. This may seem humorous to the experienced teacher, but it can be detrimental to the untrained and/or inexperienced educator who is searching for new techniques to apply with his or her students.

There is a prevailing attitude of "write makes right" in the field of special education that induces some educators to accept most of what they read in professional journals as being good and positive practices. There certainly are many excellent studies published, but the inexperienced teacher may be unable to discern between those that are good and those that are not. The result is a "reinventing of the wheel" that deaf-blind education can scarcely afford.

Efforts must be made to identify practices that have consistently proven effective in promoting functional skills acquisition by deaf-blind children and youth. A priority should be placed on the identification and validation of methodologies that foster independence across natural environments. Noonan and Reese (1984) recommend that three questions be asked when investigating the validity of an intervention procedure:

1. Did behavioral change occur as a function of the educational intervention procedure?

2. Did the educational intervention occur as prescribed in the treatment plan?

3. Is the resultant behavioral change meaningful to the student (i.e., is it one that he/she has reason, motivation, and opportunity to apply in school, home, and community environments)?

Positive practices from outside the field should also be investigated for potential application with the deaf-blind population. Ineffective techniques must likewise be identified and made known. The optimum product of these activities will be consistency in the provision of appropriate educational services to students across the country (Smith & Tawney, 1983).

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CHAPTER 6

THE EDUCATION OF DEAF-BLIND STUDENTS: PRIORITIES FOR RESEARCH

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The charge assigned to Core Area Group 3 was to identify and prioritize the needs of deaf-blind persons which might be ameliorated through education or school-based research. The members of this group interpreted their charge as being to focus attention primarily on one of the many broad areas of concern. Unanimously the group chose to identify and prioritize the needs of deaf-blind persons completing their eligibility for educational programs and preparing to enter community settings which might include independent living situations. Members of this group, as well as other conference participants, recognized that educational services are often desired by deaf-blind persons throughout their lives. Research on the types of educational services most appropriate for deaf-blind persons at various life-stages and investigations of the manner in which such services would be most effectively delivered remain to be identified and prioritized. Although not specifically addressed, concerns were expressed for educational research into the needs of children at-risk of becoming deaf-blind as a result of Usher's Syndrome and for continuing education services for deaf-blind adults. Although not an educational service, concern was also expressed for research into the training needs of deaf-blind adults.

The members of the Core Area Group 3 agreed that deaf-blind persons would have the greatest chance of successfully accomplishing the transition from an educational program to a community setting if their education had included at least a working knowledge of communication techniques, orientation and mobility skills, and procedures for independently performing the activities of daily living. More traditional education in academic areas was also considered important for deaf-blind children with sufficient cognitive ability. The hope was also expressed that the Massachusetts model of designating a Transition Team with representatives from several community service agencies would be adopted by other states. A Transition Team could determine the minimum skills levels deaf-blind persons would need prior to leaving an educational program. The team might also monitor community services to deaf-blind persons as they become acclimated to community living.

With these understandings established, the members of Core Area Group 3 began to identify and clarify concerns which might be addressed through educational and school-based research. Approximately 50 concerns were expressed and ranked using a nominal group (weighted ranking) process. The 20 most urgent issues are presented below as they are prioritized by the group. As recommended in the literature on school-based research, the group recommended that research on each of the concerns identified (a) be conducted in "natural" settings and (b) be a longitudinal investigation (Blea & Overbeck, 1977; Curtis & Donlon, 1984; Stainback & Stainback, 1984; Yoshida, 1984).

The area of greatest concern is that of preparing deaf-blind persons to accomplish the transition from educational programs to community situations. A transition plan should be formulated for each deaf-blind person to insure that s/he be instructed in the skills required to enter a community situation. Specifically, a longitudinal study is proposed to address the following question:

* What factors have the greatest positive impact upon the development and implementation of a plan to facilitate the transition of deaf-blind persons from educational programs to community situations?

Among the factors to be investigated are current service delivery models, and the content of typical curricular and school staffing patterns. The study is longitudinal in that the educational accomplishments of deaf-blind persons are to be investigated in a number of different settings. Upon completion of their educational program, the function of these deaf-blind persons in community settings will be investigated at regular intervals for a number of years.

Of second greatest concern are services to deaf-blind infants and older pre-schoolers. At what age should educational services begin in order to be of greatest benefit in preparing deaf-blind children to become adults capable of living independently or semi-independently in community settings?

* What are the needs, skills, and objectives of appropriate educational programs for infants and preschool students? Research should focus on (a) effective intervention strategies, and (b) determination of "critical times" for intervention.

There are no questions as to the importance of early intervention. Rather, research is needed into effective intervention strategies.

The third priority for educational and school-based research is that of the effectiveness of various educational placements. How well do each of the currently used educational service delivery options prepare deaf-blind persons to function independently or semi-independently in community situations? This concern may be addressed through research on the following question:

* What are the strengths and weaknesses of the various placement options in providing educational services to deaf-blind persons in preparation for their function in educational and post-educational community settings?

Among the educational placements needing investigation are (a) age-appropriate "mainstream" settings, (b) age-inappropriate "mainstream" settings, (c) self-contained classroom settings, (d) segregated day-school settings, and (e) residential school settings.

The difference among deaf-blind persons and in their geographic locations necessitates a second question:

* Does the effectiveness of educational services differ depending upon (a) the ages of the children being served, (b) the cognitive abilities of the children being served, and (c) the geographic setting in which the children are being served?

Geographic setting refers to whether services are being provided in a rural as opposed to an urban setting.

The next priority selected by the working group is the need for the deaf-blind persons to learn to be independently mobile. There was agreement about the developmental importance of independent mobility. Orientation and mobility were also recognized as critical elements if a person is to participate in community activities. This concern is expressed in the following question:

* What techniques and procedures are most effective for teaching orientation and mobility skills to deaf-blind persons?

Research should focus on (a) the impact of early training experiences; and (b) techniques and procedures for students who have disabilities in addition to deaf-blindness, including students who are orthopedically impaired.

The fifth research priority addresses the effects which characteristics of the deaf-blind children receiving services may have on the setting in which services are being delivered. This concern may be examined through research on the following questions:

* Which student characteristics (e.g., educational needs; age; etc.) influence educational placement in alternative service delivery modes (e.g., segregated day school; self-contained class or age-appropriate regular school site; etc.)?

* What characteristics of a deaf-blind student should be considered in determining the setting in which that child would receive the most educational services?

Included among the student characteristics to be investigated are (a) residual auditory and visual functioning, (b) other sensory or physical disabilities, (c) cognitive limitations, and (d) other educational needs. Among the educational settings to be considered are (a) age-appropriate "mainstream" settings, (b) self-contained classroom settings, (c) segregated day-school settings, (d) residential school settings. Particular attention should be focussed on the type of residential school best suited to meet the needs of particular students. That is, what factors determine whether a deaf-blind child will be served in a residential school for the blind as opposed to a residential school for the deaf as opposed to a residential school for the deaf-blind?

Two concerns are involved in the sixth research priority. The first addresses the factors which influence a deaf-blind person's ability to become a participating adult member of a community. The second deals with the effectiveness of community-based as opposed to simulated settings. The first of these concerns may be addressed with research on the following question:

* What factors determine whether a deaf-blind person will become integrated into a "natural" community setting after s/he becomes 22 years of age?

Among the factors to be considered are (a) the types of educational and training services mastered, (b) the setting in which education and training services are provided, and (c) participation in continuing educational or training services.

The second concern assigned sixth priority may be addressed through research on the following question:

* Does community-based instruction result in greater skills acquisition and independent functioning in "natural" community settings than does instruction in settings which are not community-based?

Settings which are considered community-based for the purposes of this investigation would include classroom settings as well as simulated community settings.

The seventh priority for research includes two concerns. The first is the need to identify techniques for teaching deaf-blind persons the transferable vocational skills and the vocational success skills they will require for employment. This concern may be addressed through research on the following question:

* What are the most efficient procedures for teaching deaf-blind persons the transferable vocational skills they require to become employed in either a competitive or a sheltered setting?

Among the transferable vocational skills addressed in this question are (a) bi-manual coordination, (b) hand-foot coordination, (c) frustration control, (d) finger dexterity, (e) kinesthetic memory, and (f) memory for sequence of operations (Richterman, 1982), (g) work proficiency, (h) work rate, (i) work quality, (j) work perseveration level, (k) work repertoire, and (l) work endurance (Wehman, 1981, p. 19-22).

Also ranked as seventh priority for research is investigation of the effects of the isolation often imposed by a dual sensory loss. This concern may be addressed through research on the following question:

* What are the effects of the dual sensory losses of deafness and blindness upon the pyscho-social adjustments of deaf-blind persons? Among the adjustments to be investigated are the manner and extent to which deaf-blind persons adapt to (a) home, (b) school, and (c) work.

Of equal concern is the need to identify procedures through which the residual auditory or visual functioning of a deaf-blind student, when present, can be preserved or enhanced. This concern can be addressed through research on the following question:

* What techniques will assist deaf-blind persons to maintain or enhance their residual vision and hearing?

In part, this question is based upon the assumption that a deaf-blind person's ability to function will be enhanced through utilizing perceptions of sight and sound.

The concern of next greatest importance to the working group is to determine the effects of categorical educational placements of deaf-blind persons. This issue may be addressed through research on two questions:

* What criteria should be used to determine appropriate categorical placements for deaf-blind persons?

* What are the effects of placing a deaf-blind person in each of these categorical educational or training placements?

Among the categorical educational and training placements to be investigated will be placement in a classroom or school for the (s) blind, (b) deaf, (c) multiply disabled, (d) cognitively limited, or (e) deaf-blind.

Tenth priority for educational or school-based research was assigned to the implications of progressive sensory losses on the education of persons at-risk of becoming deaf-blind and on the preparation of children and youth who will have diminished residual hearing or vision. This concern may be addressed through research on the following question:

* What educational or related services will maintain or enhance the functional abilities of deaf-blind persons who are experiencing progressive sensory loss(es)?

Discussion focused primarily on the educational and training services to be provided deaf children and youth who are expected to become blind as a result of Usher's Syndrome. That is, should these individuals be taught some of the techniques used by blind persons prior to becoming blind themselves? Among the skills which might be taught are (a) braille and (b) orientation and mobility using a long white cane. At issue is whether instruction in these techniques would reduce the stress many persons with Usher's Syndrome experience when anticipating the onset of visual disability. Also in question is whether teaching these techniques early in life will eliminate, or at least minimize, the potential interruption in family and vocational pursuits which often accompany the onset of blindness.

Two "communication" issues were assigned eleventh priority. The first concern addresses the needs of members of the family of a deaf-blind person to have accurate information which will facilitate their interactions with one another. The second concern focusses on developing

procedures to facilitate communications among the inter-disciplinary and inter-agency teams which serve deaf-blind persons. The first concern may be addressed through research on the following question:

* What are the most effective techniques for teaching the members of the family of a deaf-blind person the skills required to maintain the deaf-blind person as an active family member?

Most members of families of deaf-blind persons have neither the information nor the behavior management skills often required to maintain a familiar relationship with a deaf-blind person.

The second concern may be addressed through research on the following question:

* What are the most effective procedures for encouraging and enhancing communications among the various professionals and para-professionals who serve deaf-blind persons?

Among the service providers identified were (a) audiologists, (b) educators, (c) eye care professionals, (d) rehabilitiation professionals, and (e) social workers.

Twelfth priority for research was assigned to the communication needs of deaf-blind persons themselves. This concern may be addressed through the following question:

* Which approach, or combination of approaches, is most effective in developing communication skills for deaf-blind persons?

Among the language and communications instructional techniques identified were (a) the behaviorial approach, (b) the vanDijk technique, and (c) total communication. It was noted that the most appropriate instructional techniques will differ depending upon the sub-population of deaf-blind persons being considered. These sub-populations include (a) persons who have insufficient residual hearing for verbal communication but sufficient residual vision to read sign language, (b) persons with insufficient residual vision to read sign language, but sufficient residual hearing to communicate verbally, and (c) persons with insufficient hearing to communicate verbally and insufficient residual vision to read sign language.

Next highest priority was assigned to the identification of teaching deaf-blind persons the functional skills required for community living. This concern may be addressed through research on the following question:

* Which curriculum model, or combination of curriculum models, is most effective in developing the functional competencies used by deaf-blind persons?

Among the curriculum models to be investigated are (a) the developmental approach, (b) the behavioral approach and (c) the community adaptation approach. Here again, the effectiveness of each model may be influenced by a number of factors. Among the factors having potential impact on a model's effectiveness are (a) differences in the characteristics of the sub-populations of deaf-blind persons, (b) the age of members of the sub-population, (c) varying physical and cognitive abilities of members of the sub-population, and (d) the various geographical and instructional settings in which the model is used.

Attention was next focussed on the competencies desired in the teachers of deaf-blind children. Very specific concerns were expressed as to the qualifications most desirable in the instructional personnel interacting with deaf-blind persons. Research on a number of questions is required:

* What informational and performance competencies are required to utilize fully the learning potential of deaf-blind children and youth?

* Which competencies in a teacher of deaf-blind children or youth are predictors of independent functioning by those students?

* Are different teacher competencies required to instruct deaf-blind persons (a) of various sub-populations, (b) of different ages, (c) of differing physical or cognitive abilities, (d) in differing service delivery models, and (e) in different geographic settings?

* What pre-service and inservice education and training techniques are most effective in developing and maintaining desired teacher competencies?

Research into these questions might improve educational services to deaf-blind persons and reduce teacher "burnout".

Priority was next assigned by group members to the efficiency of currently used assessment procedures. This area of concern may be addressed with research on the following question:

* How effective are the procedures used to assess deaf-blind students with respect to (a) the identification of strengths and weaknesses to be addressed in the formulation of an

individualized education plan, (b) student activity during school and non-school hours, and (c) the evaluation of the intervention strategies being used with a particular student.

Among the procedures to be investigated would be (a) existing tests and measures, (b) school and non-school environments, and (c) procedures for conducting reliable and valid systematic observations of student performance.

The next highest priority for educational and school-based research was assigned to two areas. The first concerned instructional techniques currently in use with deaf-blind persons of average or above average cognitive ability. The second concerned the most effective student-teacher ratio for educating or training deaf-blind persons. Investigation of the following question is recommended:

* How effective are the various techniques currently being used for educating deaf-blind persons of average or above average intelligence?

Particular concern was expressed for the instructional needs of multiply disabled, sensory impaired persons. Among the factors to be included in this investigation are (a) appropriate practices and procedures and (b) the effectiveness of existing service delivery models.

The other concern at this priority level may be addressed through research on the following question:

* What are the most effective instructional arrangements for educating deaf-blind persons?

Among the instructional arrangements to be investigated in this study are (a) one-to-one instruction, (b) small group instruction, (c) large group instruction, and (d) semi-structured instruction. These investigations should also determine the appropriateness of each of the these techniques for several sub-populations of deaf-blind persons enumerated above. Finally, the potential effects of either over- or under-using each of these instructional arrangements is to be explored.

Group members were most highly concerned next with non-oral communication techniques being taught to deaf-blind persons. This concern may be addressed through research on the following question:

* What is the most effective communications technique for members of each of the sub-populations of deaf-blind persons?

Among the non-oral communication techniques for members of this population to be investigated in this study are (a) signs, (b) photographs or pictures, and (c) electronic or mechanical devices. Criteria must also be established to predict which communications technique will be of most benefit to particular deaf-blind persons.

Eighteenth priority for reseach was assigned to the potential educational benefits of interactions between deaf-blind and non-disabled persons. This concern may be addressed through research on the following question:

* What are the educational consequences of structured interactions between deaf-blind and non-disabled persons?

The effects of such interactions should be examined in (a) social, (b) educational, and (c) community situations.

Group members were next most concerned with identifying procedures for evaluating instructional techniques and materials in such a manner as to result in positive change. This concern may be addressed through research on the following question:

* What procedures may be used to evaluate educational and training services to deaf-blind persons which may lead to positive changes in programs?

Emphasis was placed on the requirement that such evaluative techniques shall be both flexible and comprehensive.

Twentieth priority for education or school-based research was interest in the effects of nutrition on the performance of deaf-blind persons. This concern may be addressed through research on the following question:

* What are the effects of nutrition on the behavioral performance of deaf-blind persons? The effects of changes in diet should be assessed on, e.g., (a) educational performance, (b) physical ability, and (c) general health.

This concludes the concerns that the members of Core Area Group 3 ranked among their highest priorities for educational and school-based research. The members of the group believe that each of these concerns, as well as the other twenty-five concerns identified (listed in Appendix A) should be researched. Recognizing that funds for research, however badly that research is needed, are limited, the team prioritized their concerns to assist the various funding agencies in determining the most worthy projects to be funded. The members of the group also expressed their hope that conferences would be convened periodically in future years to prioritize the needs of deaf-blind persons which may be addressed through educational or school-based research.

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CHAPTER 7

ISSUES CONSIDERED IN VOCATIONAL TRAINING OF THE DEAF-BLIND PERSON

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In an attempt to develop a paper on the vocational training of the deaf/blind individual, it became very quickly apparent that little or no research has been conducted based upon the traditional research model. What is available in the literature is information descriptive of programs which have been developed and implemented. These reports, along with personal observation, have generated a number of issues which need to be addressed from the more traditional research standpoint. This paper will, therefore, present and discuss those issues.

HETEROGENEITY OF GROUP

The label of deaf-blind has been applied to three, quite distinct groups of people. The original group who were categorized as deaf-blind were people who, quite often, were congenitally sensory impaired in one or the other areas, thus developing skills built on the non-involved sensory apparatus. This group of individuals, quite often having Usher's Syndrome, are more often in the range of intellectual functioning from mildly mentally retarded to intellectually normal and above.

Another group categorized as deaf-blind are people who are deaf-blind due to conditions such as rubella, which attack not only the sensory organs of the individual, but also other organs of the body, including the brain. The majority of these individuals are congenitally deaf-blind, and because they most often do not have a sufficiently "non-involved" sensory apparatus, they often do not develop sophisticated skills of language, social interaction, or cognition. Descarge (1982) presents, in chart form, a very adequate description of these two groups both in the areas of, what she calls, a "Living Tract" and "Educational and Vocational Tract". Orlansky (1982) also supports the heterogeneity of the deaf-blind population, stating that such necessitates an array of living and day services. He goes on to say that because of the heterogeneity of this population, it is imperative that they have access to varied interdisciplinary services.

In addition to the above described groups, there is at least a third group of people who are so intellectually and/or medically involved that they will most likely be unable ever to move beyond the total care environment of a skilled nursing facility. The primary disability of this particular population is its medical and/or intellectual deficit. Vision and hearing impairment are generally considered secondary handicapping conditions for this population.

Deaf-blind individuals must be given opportunities to learn skills and integrate into the world around them. Although there are certainly deaf-blind individuals who are so profoundly involved they will most likely not integrate successfully into the world of work, we also know of individuals declared ineligible for service through Vocational Rehabilitation because of unrealistic expectations for employment following VR service.

FUNCTIONAL EVALUATION

The most appropriate approach to take in assessing the potential and limitation of the deaf-blind person has been a subject of much discussion. There is concensus that the traditional instruments, based upon normative approaches, are totally inappropriate for this population. Orlansky (1982) emphasized that the basic assessment must concentrate on observable, functional skills that a deaf-blind student can demonstrate. He also emphasized the importance of not only evaluating a person but of developing a treatment or habilitative plan for the person based upon the results of the evaluation. The question has been raised, "If you are going to diagnose and not treat, then why diagnose?" Simpson (1983) has emphasized the importance for evaluation to be based not only on the limitations of the person, but also on his/her assets. Further, evaluation of limitations and assets should be based on observation over a period of time and in a variety of settings.

An effort to develop a protocol or procedure for evaluating a person along a dependency/interdependency continuum is one which should be explored and offered as an approach to those who are beginning to work in this particular area. The term "interdependency" is proposed, rather than the more traditional term "independency", as a means of emphasizing the various support systems which must be drawn on for the deaf-blind individual to develop to his/her full potential. The term "interdependent" emphasizes the importance of our viewing deaf-blind clients as <u>both</u> "givers" and "receivers". The importance of evaluating the person over a period of time and observing that person in varied situations is presented by many for consideration. The work which has been done by Iceman (1984) is another very significant approach to such an opportunity.

PERSONALITY

One of the personality characteristics related to "employability" is the characteristic of perfectionism seen in many deaf-blind people. People who are both deaf and blind or severely multi-sensory impaired, by necessity, must become quite careful in the tasks they undertake. While this "trait" is adaptive in many ways, from a vocational--especially assemblyline--standpoint, it is detrimental to their production (Cotten and Wade, 1984) and may cost the deaf-blind employee money. From the experience of these authors at Opportunities Unlimited, "external" quality control on the production line was not necessary, as the deaf-blind workers conducted their own quality assurance.

Efforts need to be made to develop a procedure whereby the deaf-blind person who does his own quality control, is motivated to work faster, even though the error rate may rise. It will be necessary for the person to learn that in the assemblyline setting, speed is as important a variable as is correctness, whereas in other settings the necessity of correctness is the prime variable about which to be concerned.

SOCIAL SKILL TRAINING

A point which is emphasized by many (Dildy, 1982; Goros, 1983; McGinnity, 1983), is the importance of implementing a community-based vocational training program for deaf-blind individuals. The opportunity to be integrated with non-disabled co-workers in actual job settings where work demands are realistic and role models are available is a definite asset. One of the points emphasized is the necessity of exhibiting appropriate social skills for the world of work, since often---particularly in special schools and settings developed to serve the handicapped citizen--service personnel tend to tolerate what would otherwise be viewed as aberrant behavior. By being involved in the community with people who are not "professionals" in this field, the handicapped person encounters disgust and ostracism because of his/her deviant behavior and often develops more socially acceptable behaviors, given this "normative" social pressure.

Emphasis has been placed on the provision of proper vocational training, follow-up and support to deaf-blind inidividuals in the rehabilitation setting, enabling them to improve their independent performance of work-related tasks, their ability to communicate with employers and co-workers, and their work productivity.

Dildy (1982) emphasized the importance of teaching communication skills to the deaf-blind individual as a means of helping the person become aware of the social situations (and thus, develop the necessary social skills) which are an inherent part of the everyday work situation. Individuals working in competitive employment must be capable of some level of

communication. Providing the non deaf-blind person skills in communicating with a deaf-blind individual through one of the augmented speech methods, and desensitizing the person so that they feel more comfortable in being around and attempting communication with a deaf-blind person cannot be overlooked when one is discussing vocational placement and follow-along for the deaf-blind individual.

VOCATIONAL SKILLS

Questions are often raised regarding what vocational skills should be taught and what setting will provide the most appropriate vocational training ground. Orlansky (1982) supports the opinion of others that vocational skill training should be in settings that closely resemble actual agencies so that the time needed to teach given tasks is most efficiently used.

The approach utilized by co-operative education has much merit as it provides for a transition from the educational environment to the world of work and outlines the expectations of the worker role. Co-operative education also facilitates co-planning between education and vocational rehabilitation as a common goal.

DEAF-BLIND CHILDREN BECOME DEAF-BLIND ADULTS

The importance of coordinated and cooperative efforts among agencies to meet the service needs of this population cannot be emphasized enough. This is a particularly important task for educators and rehabilitation workers. Historically, the training of teachers has focused on instruction for students which emphasizes the development of "academic" and "intellectual" skills, with minimal attention to "job skill training" or pre-vocational knowledge. Coordinated efforts between educators and rehabilitation workers can "bridge the gap" between school and the world of work, and can better prepare the young handicapped student for an independent life away from the confines of 24 hour supervision.

Every writer included in the bibliography of this paper spoke to the need for communication, cooperation and coordination. Baud and Tweedie's survey (1982) predicted that cooperation between rehabilitation, education, and community agencies will increase as service needs for the deaf-blind population continue to be identified.

IMPORTANCE OF COORDINATED AND COOPERATIVE ENDEAVORS PUBLIC AND PRIVATE

One of the examples of a successful program of vocational and support services for the deaf-blind person is the Opportunities Unlimited Program in Mississippi (Cotten and Wade, 1984). Highlights of why the program appears so successful are based upon the following contributing agencies.

1. A private sector agency (Royal Maid Association for the Blind, Inc.) operates as a successful business employing individuals who are blind. To expand and obtain additional work it was necessary to add to the number of blind workers.

2. Ellisville State School, a residential facility for mentally retarded people, assumes the lead role in meeting the needs of deaf-blind individuals in Mississippi. The state school identified the need for the meaningful day services for their deaf-blind population, and had space and staff which could be allocated for engaging the residents in such services. In addition, the School had state funds which could be matched for construction and renovation of facilities.

3. Vocational Rehabilitation Services for the Blind was interested in having individuals referred for evaluation and possible addition to their service rolls. The ability to obtain additional successful closures was also of interest to the counselors and the administrators.

All three of the above agencies, two public and one private, entered into an arrangement whereby they could, by cooperating, complement the efforts of each other. The fact that each entered into the arrangement not only to meet the needs of another agency; but also to help meet their own, facilitated the willingness to cooperate, communicate, coordinate, and compromise. Advantages outweighed disadvantages many times over, and at the present time, deaf-blind individuals whose previous options were extremely limited now may be earning in excess of $1,000 a year and may be having the opportunity of moving into a less restrictive environment.

TWENTY FOUR HOUR PROGRAMMING

The importance of programming for the deaf-blind individual on a 24 hour basis cannot be emphasized enough. For many deaf-blind individuals to be successful it will be imperative that their entire 24 hour day be assessed and plans made to meet their needs throughout the day.

Simpson (1983) proposed that it is necessary to develop programs simultaneously in the areas of vocational, social, personal, and community adjustment services in order to develop the person maximally. This requires the coordinated and cooperative effort of a number of agencies, both public and private. The success of the program discussed by Cotten and Wade (1984) is due to this type of effort. Without the assistance of each of the service providers involved, the work would not be successful. No longer can we compartmentalize or segment people.

As Orlansky (1982) points out, the heterogeneity of the population makes it imperative that deaf-blind individuals have access to varied interdisciplinary services. With the non-multisensory impaired person, it might be possible to have the traditional approach to vocational rehabilitation--that of being primarily concerned about work. With this population, it is necessary that the total person and his/her needs be considered and met if that person is to be vocationally successful.

Hawkins (1981) addressed the obvious need for deaf-blind persons to receive more than just work skills from the rehabilitation program. Among many other needs, he proposed that deaf-blind individuals must be provided instruction in how to travel to and return from their future work sites. Cotten, Long & Askew, (1979) and Sunbelt Regional Center for Deaf-Blind Children (in press) have expanded upon this notion of total life planning for the deaf-blind person.

FEDERAL POLICIES AS IMPEDIMENTS TO VOCATIONAL PLACEMENT

Three major issues must be addressed and possible solutions provided, regarding ways in which federal policies tend to serve, without intention, as impediments to vocational placement for deaf-blind individuals. These issues include the following.

1. Supplemental Security Income (SSI) has deterred some people and/or their families from working. The length of time needed to become eligible develops a fear in the minds of some people that once they are on SSI, they will do everything possible, including not working, in order to remain a recipient. Another major problem connected with this is that by being an SSI recipient, one is eligible to participate in the Medicaid reimbursement program. With the medical difficulties many of these people experience, they cannot afford to work if by working, their eligibility for Medicaid will be cut. There needs to be a procedure developed whereby the person, with justifiable medical costs in excess of what he is able to pay, can still be eligible for participation in the Medicaid program.

2. The requirement now exists that the person who is vocationally successful must then be closed without follow-along services being available. Follow-along or case management services may be necessary for the duration of the deaf-blind person's life. It is true that the person may be vocationally successful, but without the alternative living arrangement and other support services being made available, the person has an excellent potential for becoming vocationally unsuccessful. The role of the Vocational Rehabilitation counselor in this endeavor may be to insure that the person becomes eligible for case management services provided by another agency such as Mental Health, Welfare, etc. The counselor's role is not to maintain that responsibility on a life long basis.

3. The current definition of a Work Activity Center emphasizes that monetary remuneration is not the key ingredient, but rather, that the activity of work itself should be the principal concern. This definition does not relate well to the reality of clients in a work activity center. The clients with whom we have worked are very aware of the money earned and the fact that without that money the things which are reinforcing (such as soft drinks) will not be available to them.

SUMMARY

In summary, this paper has made an effort to introduce and briefly discuss some of the more pertinent issues which must be addressed if the deaf-blind person is to have the opportunity to be successful as an adult. Efforts made during the education years must be continued as the deaf-blind individual reaches adulthood, or the benefit of those many years of instruction can be wasted. Of utmost importance is to ensure the deaf-blind citizens training which will allow them to integrate into our society to the greatest extent possible. As Helen Keller so aptly stated, "it's not enough to give the handicapped life -- they must be given a life worth living."

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CHAPTER 8

REHABILITATION AND JOB SKILLS DEVELOPMENT: NEEDS OF THE DEAF-BLIND POPULATION PRIORITIES FOR FUTURE RESEARCH

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Underpinning the discussion and development of rehabilitation and job skills development research priorities in the field of deaf-blindness was the basic assumption that people who are deaf and blind can be participating, productive, and wage earning members of society. It was acknowledged that this statement of belief was also a goal for the rehabilitation and education community, for too few deaf and blind individuals achieve the goal of full productive participation in society. The second assumption made was that appropriate and practical research can be used in the field of deaf-blindness to assist people who are deaf and blind to achieve the goal of full participation in society.

It was acknowledged that there is woefully little rehabilitation and job development research in the field of deaf-blindness. The research priorities developed for this area of rehabilitation research reflect the lack of research and a generally deprived state-of-the-art in research when the questions posed are compared with others in the field of rehabilitation. Consequently, the priorities identified are accompanied by a sense of urgency because the rehabilitation and job skills development research needs are vital and immediate.

The Rehabilitation and Job Skills Development Group identified thirty-two research initiatives. These 32 initiatives were categorized into five major areas. By priority (highest first), the defined areas include the following:

1) occupational status, consumer, and worker issues;
2) professional worker issues;
3) employer issues;
4) rehabilitation process issues;
5) medical issues.

OCCUPATIONAL STATUS, CONSUMER, AND WORKER ISSUES

There is a dire need in the field for a data base on deaf-blind adults. The field needs to know how many deaf-blind persons there are, where they are, and the kinds of situations in which they are involved. The data base must extend beyond surveys of state agency directors, to the collection of data involving head counts and in-depth interviews with deaf-blind persons, employers, co-workers, counselors, family members, and significant others. Models of successful data collection, integration, and analyses are found in research literature in the field of deafness.

Specific research initiatives identified for this area include the following.

1) Description of the characteristics of deaf-blind workers (vocational/social skills) associated with job retention/acquisition/promotion across continuum.

2) Identification of jobs held by deaf-blind persons, including such factors as length of time in employment.

3) Identification of the factors leading to successful peer relationships at work for the deaf-blind worker and non-disabled or disabled (not deaf-blind) peers.

4) Development of training and awareness programs to assist peers and employers to relate to deaf-blind people.

5) Demonstration of training models for skills needed (social/vocational) by deaf-blind persons in the work place.

6) Identification of factors which contribute to successful employment of deaf-blind persons at professional/technical/managerial levels. (DOT codes 0-1)

7) Identification and description of self-employment opportunities for deaf-blind persons (not limited to home based).

PROFESSIONAL WORKER ISSUES

The second tier of priorities included those which are associated with the professional who works with deaf-blind persons. There is an urgent need to identify training needs of professional workers in deaf-blindness

and to identify strategies to meet those needs. Because of the myriad of rehabilitation service needs of the deaf-blind individual, services from a number of separate disciplines are provided deaf-blind individuals. To assure service integration, cross-disciplinary training at pre-service and at continuing education levels is needed.

While seven research needs were identified, one issue stood out as particularly pressing in importance. The field of deaf-blindness, because of its cross disciplinary nature, needs a common language. To reduce the number of communication problems, it is recommended that a document be developed which lists the present terms, definitions, and applications of the verbal symbols of deaf-blindness language. Groups which may potentially benefit from such a glossary include interpreters, consumers, employers, families of deaf-blind persons, and professionals. The research needs identified in this area include the following.

1) Development of a glossary of terms, with government and business validation, related to deaf-blindness.

2) Development of models of effective on-the-job-training for vocational rehabilitation counselors working with deaf-blind clients, with emphasis on job development and placement.

3) A study of the effect of job stress and "burn out" of professionals serving deaf-blind clients on the quality of services extended to those individuals.

4) Identification of strategies to prevent burn out/reduce stress for the professionals working with deaf-blind clients.

5) A study of the expectations of vocational rehabilitation counselors working with deaf-blind clients; establishment of criteria for ceasing vocational rehabilitation services and for other systems assuming some responsibilities vis-a-vis this population.

6) Development of appropriate curriculum models for training rehabilitation counselors (pre-service and in-service) to work with deaf-blind individuals. A study of the effects of such training on service delivery and quality.

7) A study of deafness and blindness professionals, and their perspectives on the "other" disability.

EMPLOYER ISSUES

The third level of priorities focuses on employer issues. The major thrust of the research in this area needs to focus on strategies to overcome obstacles in the hiring, retention and promotion of deaf-blind

persons. The research priorities in this area are based on the previously stated assumption that deaf-blind persons are capable of being good employees. The research priorities identified include the following.

1) Identification of the characteristics of employers who hire, retain and promote deaf-blind employees along a continuum of continuing employment opportunities.

2) Identification of employers' strategies in dealing with disabled employees who acquire second and third disabilities; i.e., the deaf worker who becomes blind or the blind worker who acquires adult hearing loss.

3) Description of the effect of employer cross-training demands on employability of deaf-blind persons.

4) Description of the hiring/retention practices of federal vs. non-federal contractors.

5) Identification of support resources needed by small business employers to hire, train, re-train, and promote deaf-blind employees.

6) A study of the effect of second injury clause on employer retention/hiring of deaf-blind workers.

7) Description of management styles and tools used by employers of deaf-blind persons.

8) Identification of the factors which might lead to overcoming obstacles in the hiring of deaf-blind persons.

9) Description of the costs associated with making "reasonable accommodations" for hiring deaf-blind persons, including a description of the necessary personnel support (such as interpreters, etc.)

REHABILITATION PROCESS ISSUES

A number of research efforts are needed to provide answers in this critical research area. The most overriding question identified was what kinds of rehabilitation strategies work with which group of deaf-blind people for what outcome. The following research priorities have been identified.

1) Identification of appropriate treatment and placement of different deaf-blind populations--how that relates to outcome, i.e. rubella vs. Usher's Syndrome.

2) Demonstration of least restrictive employment environment models for deaf-blind employees. Continuum from skilled nursing, work activity, sheltered workshop, industrial evaluation, competitive self employment.

3) Description of the existing service models (especially continuing service needs) for deaf-blind persons, i.e. life long case management, "shadow supervision", alternative day services.

4) Assessment/analysis of existing vocational rehabilitation and out-comes with deaf-blind clients.

5) Identification of the appropriate caseload size and vocational rehabilitation counselor skill level for working with different kinds of deaf-blind clients. (Review special education literature about this). Identification of the variables critical to successful work with deaf-blind clients, (i.e., amount of time devoted to certain areas). Description of the amount of time deaf-blind clients remain in particular statuses (i.e., extended evaluation, etc.).

6) Identification/development/description of effectiveness of assessment tools for evaluation of deaf-blind clients psychological, vocational, and social skills). Focus on dependency/interdependency continuum.

MEDICAL ISSUES

The group indicated there is a significant need for studies on the prevention of deaf-blindness. While NIHR may not be an appropriate funding source, NIHR should advocate federal fiscal support of such studies. Another need identified was to determine the medical treatment implications of the varieties of deaf-blindness and their associated physical and mental disorders. The two research priorities identified include the following.

1) Identification of measures/procedures which could potentially prevent deaf-blindness (i.e. study of retinitis pigmentosa leading to a "cure" for such progressive blindness, etc.).

2) Description of the prevalence of visual impairment evaluations and hearing impairment evaluations for those individuals already hearing impaired or vision impaired.

SUMMARY

The members of the Rehabilitation and Job Skills Development group perceived this conference as a beginning point for rehabilitation research in the field of deaf-blindness. Additional seminars are necessary if there is to be any progress in the field. Continued progress will be facilitated if, at the future seminars, employers and family members of deaf-blind persons are also invited to participate. Employers, families, consumers, and professionals impact on the achievement of full, productive participation in society by the deaf-blind person. Consequently, each group needs input in identifying rehabilitation and job skills development research priorities.

CHAPTER 9

TECHNOLOGY FOR DEAF-BLIND PERSONS

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Technology will not provide a panacea for deaf-blind individuals, but it can increase the level of functioning in many areas of their daily lives. Information typically received through vision or audition can either be enhanced or be translated into signals to be presented to other intact sensory modalities, primarily that of touch. The following pages will describe the technological approaches which have been pursued in search of partial remedies for the unique problems associated with dual sensory impairment.

Deaf-blind people, as with most sensorily impaired individuals, normally retain some useful residual sensory capability--possibly visual, or auditory, or both. For these many people, sensory aids designed for use by either the visually or hearing impaired may be of assistance. For those who are both totally blind and profoundly deaf, sensory substitution devices which utilize the somatosensory channel are used as the primary means for the presentation of information to deaf-blind persons. It will be essential to describe briefly sensory aid technology which may be of value to these individuals, but primary attention will be given to technology which employs a tactual display.

Technology is commonly used by deaf-blind people to assist them in functioning tasks related to communication, reading, orientation and mobility, and activities commonly associated with daily living (Scadden, 1981). The following discussion of aids will be organized around these functional categories. In addition, medical intervention strategies of implanting technological display instrumentation within the cochlea and the cortex deserve thorough review, but this topic will be reserved for other discussions.

COMMUNICATION TECHNOLOGY

Interpersonal communication continues to be the most significant problem confronting deaf and deaf-blind people. Deaf people with vision can rely upon a number of visual substitutes in the communication process. Sign language and visual display of printed text are the most common techniques employed. Deaf-blind individuals with some residual

vision can benefit to some degree from similar approaches. Large-character displays certainly can be used to enhance interpersonal communication. For instance, telecommunication displays for the deaf (TDDs) with magnified characters have been introduced although they are not yet widely used.

For both deaf and deaf-blind individuals who have some residual hearing, amplifiers are commonly used to enhance communication. The introduction of FM transmission systems has increased the communications capability of many severely hearing impaired individuals. These systems are comprised of instrumentation that takes the output of a microphone and translates it into a modulated infrared beam to be received and demodulated by special receivers. This technology provides greatly improved signal-to-noise ratios which significantly increase intelligibility of the speaker or audio output applicance.

Communication from the deaf-blind person to other individuals can be accomplished through a variety of techniques which do not require technology. For some, speech is sufficient, but for others, alternative techniques must be utilized--writing, fingerspelling, or communication boards which require the user to point to desired letters or words. The standard typewriter is by far the most common technological device used by deaf and deaf-blind individuals for communication. Portable TDDs are replacing typewriters because of their portability. Electronic communication boards, such as the popular Zygo Model 16, provide increased speed and flexibility in communication for the non-vocal, partially sighted, deaf-blind person.

Individuals who are both profoundly deaf and totally blind must rely upon tactile methods of communication. The manual alphabet and the printing of block-letters in the hand have been the most common means for achieving interpersonal communication. Some individuals have used an "alphabet glove", a thin cotton glove which has the letters of the alphabet and numbers printed at memorable locations. A sighted person can communicate with a deaf-blind person without knowing any common sign language merely by touching in sequence the letters that spell out a message. More sophisticated techniques, however, have made this cumbersome approach less popular.

Braille and the Morse Code are the two most common and popular means for communicating with deaf-blind individuals through the use of technology. Because the vast majority of other people do not know either braille or Morse Code, special instruments have been produced to enable

these people to use standard keyboards for the presentation of desired information. The Teletouch (Wynne, 1980) is probably the most widely used communication aid for deaf-blind people. A standard typewriter keyboard can be used by a sighted person--even using the "hunt and peck" method--and a braille keyboard can be used by those knowing braille for more rapid communication through the use of common contractions. The deaf-blind person feels a single braille character as it is mechanically raised at the touch of the keyboard.

The Teletouch became the precursor of much more sophisticated instrumentation to be used primarily for telecommunication altnough it has also been used in a face-to-face mode. The "Telebraille" is a name which has been applied to two separate systems--the first, experimental, and the second, commercial. The experimental Telebraille, developed at the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC), consisted of an electromechanical braille cell mounted on a console which contained a standard typewriter keyboard and a six-key braille keyboard. The unit also contained a "modem", an apparatus which is designed to acoustically connect electronic communication equipment to a telephone handset. The Telebraille was designed to permit deaf-blind users to communicate with one another or with a computer. (Prototypes used the ASCII code typically used by computers rather than the Baudot code typical among TDDs.)

Subsequently, Telesensory Systems, Inc. commercialized the Telebraille concept using the 20 braille character display already manufactured for its braille reading machine, the VersaBraille. This new TeleBraille (TM) has a standard keyboard, modem, and optional visual display. It has both ASCII and Baudot capability. These advanced telecommunication systems have fully replaced earlier, and relatively primitive, converted teletypewriters which had braille embossed on a paper-tape. These earlier systems had proved the viability of telecommunication for deaf-blind people; but their expense, the difficulty encountered in reading brailled paper-tape, and the size of the system combined to limit their popularity.

A far less expensive, albeit less rapid and flexible, method of communicating with deaf-blind people is provided by the use of coded signals. Morse Code provides the most flexibility, but even simple binary coding can provide valuable information. Such signal coding can be used both for communication and for signalling to the deaf-blind user. A variety of devices have been developed to provide deaf-blind people information regarding environmental sounds--fire alarms, door and telephone bells, and so-forth--and to provide a relatively primitive means for inter-personal communication. Perhaps the most versatile of these devices has been the "Tactile Speech Indicator" (Smithdas, 1977). This small, battery operated unit couples to a telephone receiver, amplifies the incoming sound, and produces a vibration which rhythmically follows it. Modulated Morse Code could be sent to a deaf-blind user with this device, but it is more commonly used on a much less technical level. A deaf-blind person with intelligible speech can call a friend, and through

a series of questions obtain responses which can be discriminated by touch. A "no" answer, for instance, could be spoken once while a "yes" could be said twice resulting in two vibrating pulses. Prior to the introduction of the Tactile Speech Indicator, the AT&T Corporation introduced a device which also provided vibratory information which was to be used primarily for tactually detecting and discriminating Morse Code. This unit was not as portable and utilized a larger disc vibrator.

The Codecom was another commercially produced device which converted environmental sound either into vibration or a flashing light to be felt or be viewed by a partially sighted deaf-blind individual. This system was meant for use primarily within the home or an institutional setting for the signalling of environmental sounds. It also contained a modulated signal which could be activated by a non-vocal individual to be used for elementary communication.

The Voice/Speech Indicator was another system which was to be used with a telephone. A sensitive meter could be viewed by a deaf or partially sighted deaf-blind person. The deflection of the meter needle indicated the rhythm and amplitude of voice communication. This device, as well as most of the other tactile and visual sound display systems, could transmit only simple messages to deaf-blind users. The exception to this rule relates to those devices which could be used by trained individuals for the transmission of Morse Code messages. The Tactile Speech Indicator, for instance, can be used to receive coded messages activated by controlled breathing or blowing into the telephone mouth-piece.

Tactual presentation of Morse Code messages has also been used for remote signalling of information to deaf-blind people. The need to produce and distribute signalling devices to be used with deaf-blind individuals has been identified by a number of rehabilitation and special education specialists as one of the most important technological needs for the enhancement of services to this population. For example, deaf-blind school children must be summoned to class, to meals, or be warned in case of fire. Several signalling devices have been developed. The most sophisticated have used Morse Code as a means for information transfer. None, however, have yet received wide distribution.

The Tactile Communicator (Kates and Schein, 1980), developed at HKNC and now produced by Sonic Alert, is the one commercially available signalling device for deaf-blind users which appears to meet the previously identified needs. This device, along with the WristCom, uses a radio signal to activate the portable unit worn by the deaf-blind user. The Tactile Communicator can signal five separate sound sources or be keyed manually. An internal vibratory system is activated at different, distinguishable frequencies indicating the origin of the signal--smoke alarm, telephone, doorbell, or so-forth. This system requires the transmitter to be electrically connected to each of the sound sources

unless it is to be operated from a keyboard. This labor-intensive installation may limit its popularity. The newest model of the Tactile Communicator also includes an optional 16-character LED display which can be used by many partially sighted deaf-blind individuals.

The Vibralert was a third radio-activated signalling system. A small transmitter could be worn by one person or be attached electrically to a sound source, such as a doorbell. The deaf-blind user would wear a small receiver, a radio paging device, which would vibrate when activated. This system, manufactured by the Bell and Howell Communications Company, may have lacked the versatility of the more sophisticated signalling devices, but it provided deaf-blind people with an affordable and viable signalling system.

An additional communications concept for deaf-blind people was investigated by the Southwest Research Institute although it did not result in a commercial product. This project was undertaken to meet the needs of the many deaf-blind persons who cannot, for various neurological reasons, master braille, but who do use the manual alphabet. An articulating, mechanical model of the human hand was developed so that it could form three-demensional representations of the manual alphabet. Each shape would be formed in response to a character typed on the keyboard of the controlling computer. Speeds of presentation approaching normal speech rates were predicted. Although this research did not lead to a commercial product, the concept appears to warrant further investigation.

A final communication aid which is beginning to show promise for deaf persons has yet to be adequately tested with deaf-blind persons. Patterned tactile speech displays--often classified together under the generic term of "vocoder" after an early research prototype--have been shown to provide deaf individuals with some useful information. Primarily, these devices are comprised of a number of electromechanical or electrocutaneous stimulators either arranged in a two-dimensional pattern or linearly. These stimulators respond differentially to specific phonemes. The sequence of dynamic patterns produced by audible speech can be used to reinforce speech as it is learned or to augment lip reading. The utility of such technology for deaf-blind persons has yet to be systematically investigated. Value in the learning of spoken language through mimicking speech produced by another speaker should be anticipated. In addition, such instrumentation can be expected to provide environmental enrichment for these sensorily impoverished individuals.

READING TECHNOLOGY

Access to the printed word is an essential part of education and of many employment situations. Deaf-blind individuals with some usable residual vision or audition can often utilize this input channel for reading with either appropriate magnification or amplification. Increased

illumination, higher contrast, and quality lens systems are adequate for many partially sighted readers. Others can benefit from electronic closed-circuit television (CCTV) magnification systems which enlarge individual characters up to 60 times in size and present white letters on a black background if desired. Similarly, individuals with some residual hearing can read with the use of recorded material and adequate amplification.

Braille is the preferred reading method for most deaf-blind individuals who lack usable residual vision or audition. Reading material can be embossed in braille on paper or stored electrically on storage media, such as cassettes, to be read with "paperless" braille reading machines (Scadden, 1982). These machines present a line of braille which is sequentially replaced by the next line of text upon command with the touch of a switch. The electromechanical braille cells are normally arranged in a single line of between 20 and 40 characters in length. The advantages of paperless braille include the fact that paper braille embossing is far more costly, and the resulting bulk of bound volumes produces a problem of storage. Up to 300 pages of braille material can be stored on a single cassette as electrical signals.

The increasing use of optical character recognition systems--such as the Kurzweil Reading Machine and the DEST Reader--is providing an innovative means for producing braille material. Printed material can be "read" by these machines, and the resulting digitized material can then be used to drive a braille embosser or be stored in a paperless braille reading machine. Deaf-blind readers should have increased quantities of braille material to read in the future; though this process is expensive, techniques are now available which can permit a deaf-blind person to read independently in braille.

The Optacon, an optical to tactile conversion system, is a reading machine which also provides blind people independent access to printed material. A small camera is scanned across a printed line, and vibrating images of each letter are displayed on the user's finger which is placed on an array of electromechanical rods. Reading speeds with the Optacon typically range between 40 and 60 words per minute, although some individuals have achieved speeds of 100 words per minute. These speeds are inadequate for the reading of large amounts of material, but the Optacon does provide immediate, independent access to virtually any printed material.

The proliferation of electronic data banks, in the emerging and rapidly expanding electronic "information society", is beginning to provide all blind people with increased access to reading material with the use of microcomputers (Scadden, 1984). In general, the microcomputer is providing increased employment, educational, and recreational opportunities for all disabled people. With appropriate sensory aid displays, deaf-blind individuals can have full access to computerized data

acquisition and transmission. Either braille or Morse Code displays can be used. Both are currently being used by deaf-blind people with complete success.

ORIENTATION AND MOBILITY TECHNOLOGY

The independent, safe travel of the blind pedestrian is achieved through a combination of sensory and cognitive processes. Obstacles must be detected and avoided while maintaining proper orientation to the desired direction and course. Familiar landmarks must be identified in order to retain knowledge regarding relationship to the environment. Potentially hazardous regions, such as busy streets, must be safely traversed. The partially sighted blind or deaf-blind pedestrian can often rely upon residual vision for many of these tasks. Enhanced illumination--as provided by portable light sources, such as the Wide Angle Mobility Light (WAML, TM)--can improve night travel for many of these individuals.

The long-cane and the dog-guide are the primary aids for totally blind pedestrians for achieving safe mobility requirements. These aids, when used properly, primarily provide safety from possible collisions with environmental obstacles. Audition, however, provides significant secondary information regarding location of both obstacles and landmarks as well as significantly increasing safety while traversing street crossings. Both ambient environmental sounds and subtle echos reflected from nearby objects provide important orientation and mobility information to the blind traveler.

The importance of audition for the independent travel of totally blind pedestrians serves to underscore the incremental orientation and mobility needs of people who are both blind and deaf. Some electronic travel aids have been developed which provide a modicum of additional assistance to some blind travelers, especially those lacking object perception, or echo localization, capability. Often these individuals lack high frequency auditory response capacity. The SonicGuide, the Nottingham Obstacle Detector, and the Trisensor, are all electronic mobility devices which provide an auditory output. With appropriate amplification, these devices may be of some value to deaf-blind pedestrians who have useful residual hearing. Three electronic travel aids which provide a tactile output, however, should be of more value for deaf-blind individuals.

The Mowat Sensor is a small, hand-held device which emits an ultrasonic beam. As this signal is reflected off of objects located within six-feet of the device, the unit begins to vibrate. The frequency of the vibration continues to change as the object is approached. This unit can be used by deaf-blind, or other blind, pedestrians to detect obstacles and landmarks.

The Lindsay Russell PathSounder was a device first designed to emit sound to signal obstacles located in front of the user. The device is mounted on the chest, suspended from a strap worn around the neck. Subsequently, vibrators were mounted in the neck strap which provided the same information formerly provided by the auditory signals. This unit was designed to provide protection for the head and upper body from overhanging obstacles which would not normally be detected with a long-case.

Finally, the Laser Cane, which was originally designed to emit three audible signals (one for drop-offs, one for obstacles directly ahead, and one for overhangs) has been adapted so that two vibratory channels can substitute for the latter two information sources. The cane itself can be used, as are other canes, to detect drop-offs, such as stairs or curbs. Each of these electronic travel aids deserve full evaluation with a deaf-blind subject population.

TECHNOLOGY FOR DAILY LIVING

Numerous aids have been developed to assist deaf-blind individuals live more productive and independent lives. Of course, many of the techniques of adapting to daily living activities commonly taught to blind individuals are equally appropriate for deaf-blind people. Braille labels, tactile watches and clocks, braille scales and thermometers, techniques for cooking and grooming, and indoor mobility skills all have similar applicability. Wherever audition normally plays a significant role for the blind person, however, special adaptations are needed for those individuals who are deaf and blind. Typically, auditory signals are translated into detectable tactile analogs. For instance, the signalling paging devices described earlier can signal the ringing of a doorbell, a telephone, alarm clock, or stove timer. Other adaptations have become relatively common, such as fans which circulate air when a doorbell is pressed, and bed or pillow vibrators which serve either as a smoke detector or alarm clock.

Some special devices deserve brief comment. Light detectors have become relatively common for totally blind individuals. These units normally emit an auditory signal, but some have been produced which present an analog vibration indicating the presence of light. Such devices are useful in detection of lights within the home or signalling lights often used in many job situations.

Deaf-blind typists do not hear the end-of-line bell indicator, but special buzzer vibrators have been developed and installed for some professional typists who are deaf-blind.

As microcomputers proliferate throughout this society, more deaf-blind individuals are expected to benefit from many of the home applications of

these systems. Many special personal applications programs have been marketed, and deaf-blind persons will be able to increase their independence, productivity, and creativity as these programs become available to them in conjunction with appropriate access sensory aid technology. Research is needed to study the appropriate employment applications of modern computer and sensory aid technology for deaf-blind people as the number of computer-based work stations multiply.

Although technology cannot fully replace the auditory and visual sensory losses, appropriate assistive devices do exist which can significantly reduce the effects of these impairments. Research is needed today to improve methods for matching technology to needs and to identify mechanisms to assist in the financing of the acquisition of these important assistive devices. Finally, research is needed to identify areas in which new techniques and/or technologies should be developed to further diminish the negative social, psychological, and economic effects of dual sensory impairments.

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CHAPTER 10

A TOUCH OF TECHNOLOGY: ISSUES AND RESEARCH PROPOSALS ON TECHNOLOGY FOR DEAF-BLIND INDIVIDUALS

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INTRODUCTION

Human beings are looking like "Superman" and "Superwomen" these days. We can open sealed metal cans, talk to people on the other side of the earth, and manipulate enormous quantities of data at break-neck speed. Of course, we need a bit of help to perform these feats, such as from the can opener, the telephone and the computer. Devices such as these may be thought of as "ability extenders"--tools we use every day to enhance our sensory and motor capabilities. The more limited we are in any domain, the more potentially useful such a tool is to us. And, as our technology becomes more and more sophisticated, the variety of tools available is increasing, thus offering an even richer array of assistance.

A new field, Rehabilitation Engineering, has grown out of the awareness that in some ways, disabled people have the most to benefit from tools, and the realization that their tools must sometimes be specially designed to meet their needs.

Devices for disabled people are sometimes extremely simple, and some have been around for a very long time (e.g., blind cave men probably used sticks to help them find their way safely, and lame cave men probably leaned on sticks), but it took the technological revolution to nurture rehabilitation engineering into the solid profession it is today.

Some major technological breakthroughs have resulted in new devices to help various disabled groups within the past decade: paperless braille displays, speech synthesizers, and electronic travel aids have revolutionized communication, and orientation and mobility for the blind, as well as provided them with greater vocational opportunities; electric wheelchairs and environmental control systems have given physically disabled individuals a degree of independence never before possible; TDD's have enabled deaf persons to use the most important communication tool there is--yet one which was not previously accessible to them--the telephone; and electronic communications systems have unlocked the thoughts and feelings of people who are non-vocal and physically disabled.

Because the new devices tap the disabled individual's intact senses or functioning motor abilities, designing devices for individuals with more than a single disability is an especially challenging task. When the multiple disability involves the two major senses of vision and hearing, the challenge is especially great. The result is that precious few assistive devices have been designed for deaf-blind individuals. Many of the technological obstacles underlying this lack of devices, however, are starting to disappear, thus giving way to optimism about the development of families of new devices for deaf-blind people.

The Technological Revolution is not only providing us with new and sophisticated devices, but it is also making them more affordable and available each year. In addition, the Technological Revolution has been epecially active in the area of primary concern to deaf-blind people--communication. Take, for example, the most popular communication device in existence--the telephone. We are suddenly finding ourselves with so many optional features available in telephones that making an intelligent decision actually requires a good deal of study and deliberation. And now we can even have this tool in our car, or make a call from 30,000 feet high in a commercial airplane! For those individuals who dare not miss a phone call, yet often aren't near a phone, remote pagers can notify the user that a call has come in. For those wishing to be private about receiving this information, pagers which vibrate rather than "beep" may be purchased.

New technology is also available for remote environmental control. Such interactions with the environment may also be thought of as a kind of communication, but one in which the user communicates with an aspect of the environment, rather than with another person. Garage door openers are almost commonplace, and modular units which can be programmed to turn lights, appliances, etc., on and off at predetermined times, are now available for use in the home.

The nature, versatility and availability of the above tools for the general consumer suggest that the basic technology for helping improve the quality of life of deaf-blind people is currently available. The specific needs of this group must be identified and then the technology molded to focus appropriately on those needs.

A group of ten researchers, each with expertise in an area of technology of special importance to deaf-blind persons, formed Core Group 5: Technological Research, at the State-of-the-Art Conference on Research in Deaf-Blindness held in Washington, D.C., November 2 - 5, 1984. The group's mandate was to present guidelines to NIHR to be used in determining priorities for technological research for the next five years which would be of benefit to deaf-blind people. The various issues and research projects presented in this paper are primarily the result of the discussions within this Group, along with important contributions from professionals in the non-technical Groups.

ISSUES

Global issues which are intimately entwined with the proposed technological research topics were identified. Those are as follows.

Demographics and Desires. The phrase "deaf-blind population" implies a group of people who, through a shared double disability of lack of normal hearing and normal vision, also share common needs. This could not be farther from reality. The phrase "deaf-blind" is one of convenience, for it encompasses a group of people so heterogeneous that precise terminology would require an awkwardly large number of descriptive categories. The result is that particular research projects or new sensory aids cannot usually encompass the needs of all deaf-blind people. Special parameters of concern include degree of hearing loss, degree of vision loss, and order in which the losses occurred. Also, the age and developmental level when each sensory loss occurred is important in influencing such factors as the development of speech and reading. Special questions include: Was hearing loss pre- or post-lingual? Was visual loss before or after learning to read? What are the primary means of receptive and expressive communication? What reading or writing system is used, if any? These parameters are all, of course, factors in addition to current age, general ability levels, living situation, educational/vocational background, interests, personality, etc.

This wide diversity seen within the deaf-blind population, along with the isolation which so often accompanies deaf-blindness, makes it extremely difficult to obtain accurate demographic information on this group. Yet, if guidelines for the development of special technology for deaf-blind people are to be formed, numbers reflecting the size and composition of the population are vital.

At least equally important is a knowledge of the desires of these consumers--that is, their needs as identified for and by themselves. It is unlikely that a disabled person would use an aid which he does not perceive as meeting any of his needs.

Luckily, there is a positive side to aiming technology at the needs of such a heterogeneous group. The large number of sub-populations within the deaf-blind group increases the number of potential new "ability extenders" which can be developed to help particular individuals. Also, this heterogeneity may allow for the use of special devices or modifications of special devices which already exist for other disability groups. For example, a deaf-blind person with enough vision to read large print may be able to take advantage of electronic magnifying systems which are newly developed for persons with low vision. In fact, for the deaf-blind person, such a tool may not only enable him to read, but may also serve as a device allowing for broader interpersonal communication.

Improving and Expanding Communication Skills. Communication requires some sort of agreed-upon code. The electronic transmission of some codes is accomplished relatively easily and inexpensively, while others are very difficult and expensive to transmit. The state-of-the-art of electronic communication uses a small number of codes. Since Roman letters (which include flat print as well as tactile letter shapes), braille and Morse Code fall into this category, learning one of the systems which are utilized in currently available transmission systems would instantly open communication channels to the users. But for deaf-blind persons who know only fingerspelling and/or sign language, these modes of communication are blocked. If, however, they learn to read braille, receive and send Morse Code, or receive tactile letter shapes, technology can tremendously enhance their social interactions as well as their vocational potential. Armed with these new skills, they would no longer require direct tactile contact for communication, but could "talk" to any literate person any place on earth.

Information Dissemination to Service Providers. Technology which is potentially useful to deaf-blind consumers is developed by large manufacturing companies, by small one-person businesses set up in garages and basements, and by all sizes of business ventures in between. It comes from research and development conducted in rehabilitation engineering centers, from private concerns, and, serendipitously, from spin-offs from NASA projects. In some instances, devices which already exist can be used without modification, but usually it is necessary to modify the functions of existing devices, or develop new products from scratch.

Keeping track of all the useful and potentially useful devices and techniques resulting from the work at this large number of diverse facilities requires a concentrated effort on the part of technical people concerned with deaf-blindness. These professionals also must possess creative insight to project how a new device, concept or procedure may have application to this disability group. Then once this information is acquired and sorted, it must be disseminated to service providers if it is to be generally utilized. This requires a regular, formal method of keeping service providers informed. Included should be not only clear information about the function of the device, but also instruction on how to use it. Too much technology is underutilized either because its existence is not known or training in its use is inadequate.

Information Dissemination to Deaf-Blind Consumers. Although the above section focuses on service providers, their "raison d'etre" in this domain is to pass the information on the fruits of technology to deaf-blind clients. For deaf-blind consumers able to access remote communication systems such as braille terminals, systems can be set up to provide direct access to this information. Such an arrangement would increase the independence of the deaf-blind information seeker, as well as allow the

consumer to explore the ramifications of information which may be of personal concern.

Quality of Life of Deaf-Blind Persons: Communication, Mobility, Vocation, and Recreation. There is probably no area of life not adversely affected by the configuration of both an auditory and visual disability. Four major categories of life activities were identified as useful groupings to be addressed by technological research. Because each is so vitally important and their relative concern for any given deaf-blind individual a matter of personal preferance, no priorities were imposed upon the categories.

Making Assistive Devices Affordable. The high cost of many assistive devices which are manufactured in small numbers is always a big problem for the disabled who tend, as a group, to have low incomes. Thus, the very group for whom assistive devices are intended are usually unable to purchase them. The problem is exacerbated for individuals with multiple disabilities, as they are a small population with a strong need for special devices, yet have an even lower average income than those with a single disability.

To solve this problem, it was emphasized that existing, and thus less expensive, technology be used wherever possible. In those instances where a new device must be designed or fabricated, third-party support might provide the funding when the disabled person cannot afford the purchase. This concept was also presented in the comments from service-providers working with deaf-blind clients who responded to a questionnaire on needs which may be addressed by technological research.

SUGGESTED RESEARCH PROJECTS

Fourteen specific research projects in technology for deaf-blind people were identified; nine of those are concerned with some aspect of communication. As with the general categories, however, no priorities were determined as each project was considered of vital importance. The need for interdisciplinary cooperation within these projects, as well as the different types of expertise called upon by the various different suggested projects, are reflected in the diversity of depth of needs and solutions as indicated below.

COMMUNICATION

The diversity of suggested projects in this area reflects the heterogeneity of deaf-blind people, as well as the rich variety of approaches which technology now has to offer. The projects address both

receptive and expressive language, direct and remote communication, sensory enhancement and substitution, and employment of existing symbol systems and development of new symbol systems.

Research on tactile communication: Braille. For years the braille code as proven itself to be a remarkably efficient system for enabling blind people to read and write. Virtually all past limitations of braille have had nothing to do with the code, but rather involved the medium for storing the code--paper. Braille books are very large, heavy and awkward to carry, as well as expensive to produce. In addition, the limited demand for braille materials contributes to scarce availability of embossed literature.

Drawbacks of braille on paper are not limited to the reading side of written communication--they also extend to the writing side. Probably the major drawback is the inability to edit once the dots are made. One might say that it's almost as if every letter punched out by the braille-writing author is "cast in stone."

Another problem faced by those writing braille has been a social one--complaints from classmates and co-workers concerning the noisiness of the braille-writing process. Whether a slate and stylus or a braille writer is used, the noise generated as dots are punched out is often distracting and sometimes loud enough intermittently to mask the speakers in a meeting or the lecturer in a classroom.

Over the past five years or so, technology has greatly alleviated all of these problems through the development of devices which retain the benefits of the braille code, yet eliminate the drawbacks of the paper. These devices use "paperless braille displays." Instead of permanent dots on paper forming the braille characters, metal dots appear along a flat surface as they are needed, and then disappear once they have been "read". Such displays are commonly 20 characters long, and are incorporated into devices such as word processors and computer terminals. Of special relevance to deaf-blind consumers is the newest device incorporating a paperless braille display. Called Telebraille, this tool enables the user to communicate over the telephone despite lack of vision and hearing.

Since there are no materials costs associated with the production of paperless braille, the cost of producing, storing, and retrieving braille information is essentially zero the user is also the typist or braillist; otherwise, it is the cost of the person hired to type or braille the information to be stored.

Another advantage of paperless braille devices is that both storage and retrievel of information is relatively quiet. The "catch" of course, is the initial financial outlay for the paperless braille device. So although these are very cost-efficient assistive devices in the long run, the majority of deaf-blind potential users are unable to afford such a multi-thousand-dollar unit.

Specific Research Proposals:

1) To take advantage of the features offered by paperless braille, it is proposed that a less expensive paperless braille display be developed in an attempt to make the devices which incorporate them more affordable.

2) The need for research to address the problem of the general unavailability of braille materials was proposed. Currently many braille items are not available in a timely fashion, and low volume materials are especially difficult to obtain in braille. In other words, whether a student needs a textbook immediately, a motivated reader wants to get his hands on the latest bestseller, or a scholar desires a copy of an obscure document, all should be readily in braille. Since major publishing companies are now putting their books on computers prior to printing, there is potential to tap into these systems so that the stored information could be converted directly to braille. This is one potential approach which needs to be explored.

Communication by Deaf-Blind People: Expanding One's World by Expanding One's Skills. The larger the number of communication systems a deaf-blind person knows, the more potential there is for technology to help expand the number of people with whom he can communicate. As stated earlier, technology can also enable the deaf-blind individual to enjoy the electronic remote communication now available to the general public. In order to reap this benefit of technology today, both English and a communication code compatible with transmission devices must be known. Braille systems are commercially available, and Morse Code as well as raised printletter shapes (such as presented by the Optacon) can be similarly adapted. The codes more commonly taught to deaf-blind individuals--finger spelling and sign language--are not currently usable as codes for transmission in remote communication.

Specific Research Proposals:

1) Technology which can enable a deaf-blind person to communicate with anyone who is literate is currently available. Its use requires a knowledge of particular codes of English. It was suggested that a concerted effort be made to teach these codes, expecially braille, to deaf-blind people so they will be able to expand their communication circle now, rather than wait for the day when a new device to accommodate their particular communication system will become available.

Communication Revisited: Expanding One's World by Expanding Technology. Not all deaf-blind people can be expected to learn braille or some other

tactile code based on English. For some, the cognitive demands for this task are too great; for others the tactile demands are too great. Yet, if these people utilize a non-English tactile system to communicate with other individuals who also know that system, it may be possible to accomodate them by developing a new device which would allow them, also, to communicate remotely. Probably an even more important gift would be enabling this group to communicate with the vast majority of people who are unfamiliar with their tactile code but can read English.

Specific Research Proposals:

1) A new device could be developed to expand the communication of deaf-blind persons who know only sign language and finger spelling. This would enable these people to communicate both face-to-face as well as remotely with persons who are totally unfamiliar with the deaf-blind individual's communication system. Although such a device might involve artificial hands capable of displaying sign language, an artificial fingerspelling hand is much more technically feasible. Such a device would also accommodate those deaf-blind consumers who lost their vision prior to their hearing, and therefore are more likely to be conversant with finger spelling than sign language.

   Author's note: Actually, a rudimentary form of just such a device was fabricated about seven years ago. The advances of technology in robotics since that time have given us the potential to develop a much better functioning and more usable model. In addition, the possibilities of interfacing such an artificial hand with a larger number of other units is increasing. For example, the output of a computer as well as the auditory information from a television set, might some day be processed for display via an artificial finger spelling hand.

Other Tactile Language Codes: Old and New. While braille has served blind people well, it has been used primarily by younger people. The fine tactile discrimination required by this code and the large number of contractions which must be memorized for the commonly used Grade II braille has tended to make learning this new skill unpopular among newly blinded older people.

Specific Research Proposals:

1) Tactile codes need not be as complex to learn as braille. Morse Code has been used satisfactorily by some deaf-blind people to transmit and receive information. Other even simpler codes have also been developed (e.g., Smitty Harris' Tapping Code), and the potential number of new ones which can be developed is infinite.

2) It was proposed that a comparative study be conducted on the relative ease of learning, information transmission rate, practicality, etc. of various types of tactile codes, especially braille and Morse Code. The purpose of such research would be to find an optimal code for deaf-blind people to learn and technical people to incorporate into designs of communication devices for deaf-blind consumers.

Tactile Displays of Auditory Information. For those who have no usable hearing or vision, touch becomes the primary channel of communication. The conventional methods of tactile communication require both parties to know fingerspelling and/or sign language. The Tadoma method is used occasionally, but very few deaf-blind people learn this difficult skill. It is also often socially unacceptable because of the intimate contact required with the sender's face.

Technology has taken some assistive steps in this area via Morse Code and braille output devices. Generally, however, these also require both the sender and receiver to know these special codes. Recently, set-ups have become available in which the sender need only know how to type. But these are non-standard arrangements involving moderately expensive equipment which is not truly portable.

Specific Research Proposals

1) The ideal communication device with a tactile output would be one which could code speech and other environmental sounds so that the input would be natural and require no special skills for the sender. Its tactile display to the deaf-blind receiver would have to contain easily deciphered information. Such a device could also be used to provide feedback to the user on the quality of his own speech. It could also be used as a simple singalling system as needed.

   Author's note: Systems based on these concepts have been developed in the past, and these have been shown to be useful but not ideal. The incorporation of today's more sophisticated technology into a system utilizing speech input and tactile output, possibly including the rapidly advancing area of voice recognition, would undoubtedly result in a much more usable and useful product.

Signalling Devices. Knowing when the doorbell rings, or the baby cries, or that someone in your house or school wants you to come to them, are simple bits of information, yet unavailable to people who are deaf-blind. If information such as this were converted to the visual domain for those who have some usable vision, and to the tactile domain for those who do not, they would be able to function more independently.

Various types of signalling devices incorporating light have been commercially available for deaf people for years, and fans have been used to signal deaf-blind people. These systems, however, tend to be awkward and restrict the user to a single area. More recently, a few tactile systems have become available, each with its own excellent features, but also with limitation. Included in the latter are that they may be awkward to use, difficult to install, difficult to decode, limited in range, may receive interference from other sources resulting in false alarms, and are usually expensive.

Specific Research Proposals

1) An affordable signalling device with visual and/or tactile display(s) is desperately needed. New available technology suggests that such a device could avoid the limitations of earlier systems and thus be easy to use, install, and decode, as well as have a satisfactory range and high accuracy.

RESEARCH ON VISUAL SYMBOLS FOR COMMUNICATION

Within the heterogeneous deaf-blind population is a large number of individuals who, through Usher's Syndrome, are congenitally deaf and lost varying amounts of vision later in life. Many of these people are conversant in sign but unable to read standard-sized print. This precludes the possibility of telephone communication via a standard TDD or the use of a computer at home or on the job. Enlarged letters are not always very helpful to these people because their tunnel vision may restrict their visual field to one letter or even less.

Specific Research Proposals:

1) A possible approach to giving this subgroup, as well as certain other deaf-blind individuals with similar communication skills, access to telecommunication devices such as telephones and computer terminals, might involve a two-part solution. First would be the development of a visual symbolic representation of manual sign which could be displayed on a two-dimensional screen, or possibly be printed. This would be followed by the development of a device which could transmit information and display it in the symbolic form and in a size and contrast optimal for the user. If the user could learn to send information via a keyboard based on this symbol system, the development of such a keyboard might be considered. A different approach which would not require the consumer to learn a new skill but which would draw heavily on sophisticated technology

would be the development of a system with a camera and an advanced pattern recognizer. By merely signing before the camera, the sender could have his message interpreted and transmitted, and then appear on the screen of the remote receiver in the symbols of the newly developed system to be read by another deaf-blind person with usable vision and a knowledge of signs, or in Roman letters for others.

RESEARCH ON IMPROVING HEARING: COCHLEAR IMPLANTS

All of the devices proposed to this point offer methods of inputting information (generally tactile rather than auditory or visual) to unorthodox sensory channels, or are modifications of the typical stimuli (e.g., enlarged letters). A more "natural" solution would be to restore the function of the disabled channel. One attempt to do this has been through cochlear implants. This work is in its infancy, and even the optimal number of channels required is unknown.

Specific Research Proposals:

1) The efficacy of cochlear implants, including an investigation of the various features such as single versus multichannel, needs to be investigated. Research comparing cochlear implants with other systems for inputting auditory information (e.g., remote signalling devices with tactile displays) is also called for. Such projects should all include subject age as a variable. The resultant information is expected to help determine the designs of future cochlear implants, as well as of other devices which encode auditory information.

ORIENTATION AND MOBILITY

Blind pedestrians who travel safely and efficiently rely heavily on environmental cues to help them maintain a straight course as well as to identify their location. Those who employ echolocation, the use of subtle sound reflections and sound shadows, have the added advantage of being able to avoid obstacles that might be too high to be detected by their canes. Sound has also proved a viable output medium for electronic travel aids by informing the blind traveler of the presence of obstacles, their distance from him, size, and even texture, as well as the location of clear pathways.

These uses of hearing are obviously not part of the repertoire of deaf-blind travelers. Given today's sophisticated technology of pattern recognition and remote communication, as well as a surge of interest in tactile displays, it may be possible to develop a sensory substitution system capable of providing enough environmental information to allow deaf-blind pedestrians to travel independently.

Specific Research Proposals:

1) The possibility of providing deaf-blind people with the appropriate real time environmental sensing, image processing, and display systems necessary for independent travel needs to be investigated. Input from orientation and mobility specialists is vital to the success of such a project.

FEEDBACK DEVICES

Both vision and hearing provide the path for information regarding the world. These are also the paths for most information about other human beings--how they look, act, and sound. Not of minor importance is the use of these sensory modalities to monitor one's own appearance, actions, and sounds. This lack of feedback sometimes results in socially unacceptable mannerisms displayed by deaf-blind people. While the majority of these sounds, grimaces, and movements are not intrinsically harmful, they decrease the individual's potential for positive social contacts and for gainful employment. The technology needed to enable deaf-blind persons to monitor these aspects of their own behavior is currently available, and compared to the sophisticated devices discussed above, is relatively "low tech".

Specific Research Proposals:

1) A collection of biofeedback devices to help particular deaf-blind persons identify and then eliminate unwanted mannerisms including sounds, grimaces, and movements, is expected to assist greatly in improving their social and vocational potential. The technology professional could develop appropriate monitoring systems based on information supplied by the service provider who has daily contact with deaf-blind clients.

ASSESSMENT

The human factors element is of vital concern in the design of any product. The lack of both normal hearing and vision to receive information, the relative paucity of knowledge about the best ways to present information tactily, the need sometimes to employ non-English communication systems, and the difficulty in assessing the learning potential of many deaf-blind individuals, leaves the product designer with a set of ambiguities about what features to incorporate into the device. The heterogeneity of the deaf-blind population complicates the situation even more. If the optimum method of operation, information encoding, and

display parameters are to be incorporated in an assistive device, a certain amount of detailed information about the end user is a must.

Specific Research Proposals:

1) In order to take appropriate human factors into consideration in the design of special devices for deaf-blind people, more information is needed regarding the sensory, cognitive, and linguistic functioning and potential of this population. Efficient gathering of such data requires the combined efforts of service providers, psychometrists, and other assessors on the evaluation team, and the designers of the new technological devices.

FUNDING

The purchasing power of deaf-blind people as a group is about the lowest there is. Few individuals with this double disability are employed, and many are institutionalized. One source of great potential in alleviating both of these dismal realities lies in devices to enhance communication, employment potential, orientation and mobility, and general activities of daily living. Unfortunately, because of the small demand, these assistive devices tend to be prohibitively expensive. When possible, costs are kept down by using or modifying mass-produced existing devices, by building spin-offs from other technologies, and by developing low-tech and simple systems wherever possible. But disabilities involving major and complex skills such as communication and orientation and mobility usually call for the development of new, sophisticated, narrowly focused devices with a unique display and a high price tag. This problem must be addressed in the development of such enabling tools so that time, effort, and money are not spent in vain.

Specific Research Proposals:

1) It is suggested that public and private policy options for assisting in the financing of the acquisition of assistive devices through model or demonstration projects be explored. This would certainly take a team effort as it would involve all the steps from identifying the need for the device through its design and development and finally its distribution to the end user.

INFORMATION DISSEMINATION

The variety of sizes and types of organiztions developing new devices and potential devices for deaf-blind consumers is enormous. The service providers and consumers wanting information about the availability of

assistive technology are widespread both geographically and in terms of specific needs. Yet the most ideal tool will remain useless until it gets in the hands of the deaf-blind consumer. Bridging the information gap is as important as developing the new device in the first place.

Specific Research Proposals:

1) Methods of providing increased access to information regarding the availability of devices and programs for deaf-blind people must be explored. Required is some vehicle (e.g., newsletter, clearinghouse, databank, etc.) which is regularly updated and easily accessed by both service providers and deaf-blind consumers themselves.

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